Development of the Cancer Survivor Profile

by

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DEDICATION

I dedicate my dissertation project to my greatest inspiration, my father, Leslie A. Todd.

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ABSTRACT

Title of Dissertation: Development of the Cancer Survivor Profile

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Purpose: The 5-year survival rate of breast cancer is now at 89% (12), amounting to over 2.9 million breast cancer survivors in the United States alone and 6.3 internationally (111; 393). The late and long-term effects of cancer and its treatment, coupled with the complexity of navigating the healthcare system in the United States, have resulted in breast cancer survivors with many unmet needs (122; 178; 196; 216; 254; 261). Currently, there is a lack of clinical assessment tools in the breast cancer population to identify problems and direct survivors to appropriate services. An aim of the doctoral dissertation study was to develop and validate a multi-dimensional measure, the Cancer Survivor Profile (CSPro), of symptoms, function, health behaviors, and health survivors needs for breast cancer survivors within the first five years post completion of active cancer treatment.

Method: The three phase development and validation process of the CSPro included: (1) systematic searches of the qualitative and quantitative literature to develop the preliminary measure; (2) Participant recruitment of breast cancer survivors who completed active treatment within the past five years; (3) Reduction of items,

determination of factor structure, and establishment of psychometric properties through principal component analyses, parallel analyses, and tests of validity and reliability.

Results: This three-step process resulted in a 76-item measure with 18 sub-scales across four problem domains (i.e., symptom burden, function, health behaviors, and health services). Construct, convergent, and divergent validity were supported for symptom burden, function, and health service needs. Each of these domains' sub-scales were internally consistent and stable over a 14 to 39 day time period. Eliminating the exercise sub-scale from the health behavior domain increased the health behavior domain's validity and reliability.

Discussion: The CSPro demonstrated validity and reliability. The CSPro has the potential to serve as a delivery system design tool to identify and direct follow-up care of non-medical problem areas in breast cancer survivors. The systematic conceptual and methodological approach to the measure's development should facilitate the integration of the CSPro into oncology and primary care settings.

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CHAPTER 1: Introduction

Breast cancer accounts for the largest proportion of survivors among all diagnoses of cancer in women (12). Following the completion of primary treatment, breast cancer survivors may still experience non-medical problems (e.g., fatigue, anxiety, physical pain, poor health behaviors) related to the cancer and its treatment (190). These problems must be identified in an efficient, reliable, and valid format prior to targeted intervention (e.g., for physical and mental side effects of cancer). However, at present there are a limited number of resources designed specifically for the identification of common problems (e.g., symptoms, health behaviors, function, health service needs) in breast cancer survivors in clinical use. The Institute of Medicine recommends the use of Survivorship Care Plans to help transition patients to cancer survivors (216). Survivorship Care Plans are individualized plans that include physical (e.g., physical pain), emotional (e.g., depression), and behavioral (e.g., physical activity) problems specific to a cancer survivor. Research indicates that the Survivorship Care Plans providers administer to cancer survivors are not consistent with the Institute of Medicine's recommendations in that medical information is more often documented than psychosocial and health behavior information (349).

The current project's goal is to construct a brief self-report measure, the Cancer Survivor Profile (CSPro), for breast cancer survivors and to augment Survivorship Care Plans or treatment summaries. Current treatment summaries include a breast cancer survivor's cancer-related diagnosis information and treatment exposure history (167). The CSPro covers domains (i.e., symptom burden, function, health behaviors, and health services) that are not comprehensively covered within Survivorship Care Plans. These

domains are included in the CSPro because the Institute of Medicine deemed them important for cancer survivor care and they are related to healthcare costs, morbidity, and mortality (129; 198; 203; 216; 233; 342; 371). The study includes three phases: 1) measure development; 2) administration of measure to breast cancer survivors; and 3) data analysis and item refinement. The project uses items from Patient Reported Outcomes Measurement Information System (PROMIS) (3) to develop the CSPro. PROMIS does not include all constructs that the CSPro was intended to measure. Therefore, for constructs not included in PROMIS, items were systematically selected from previously validated self-report scales in the breast cancer population. The study administered the preliminary CSPro via the Internet to breast cancer survivors who were within five years of completion of primary treatment. Following, analyses included principal component analysis, parallel analysis, and initial tests of validity and reliability (construct validity, convergent and divergent validity, internal consistency reliability, and test-retest reliability) to determine the measurement properties of the CSPro.

This doctoral dissertation includes a review of breast cancer epidemiology, breast cancer bio-markers, breast cancer treatment, phases of cancer, models of follow-up care, cancer as a chronic illness, the long-term and late effects of cancer, survivor care planning, instrument development, and Internet research to place the rationale for developing the CSPro in perspective. This document also consists of the study's methodology, statistical analysis plan, results, and discussion. The discussion includes a summary of the highlights of the research, consideration of findings in the context of the current relevant literature, clinical implications, study limitations and strengths, and future directions.

EPIDEMIOLOGY

The epidemiology of breast cancer is reviewed to convey how widespread the diagnosis is. In 2014, the incidence of invasive breast cancer (i.e., when cancer spreads outside of breast lobules to surrounding breast tissue) among women in the United States is projected to be 232,630 in addition to an estimated 62,570 new cases of *in situ* breast cancer (i.e., when cancer is contained within breast lobules or milk ducts) (12). Among women, the highest incidence of all cancers is breast cancer. While breast cancer is the second leading cause of cancer-related deaths in women, only secondary to lung cancer, it also has the highest percentage of survivors. The 5-year survival rate is commonly used in cancer epidemiology (172). While this time point is a convention used within oncology and most cancer deaths occur closer to time of diagnosis, it is still viewed as a major index of success. The 5-year survival rate for *in situ* disease is 99%, and 84% for invasive, regional disease in which the cancer has spread to regional lymph nodes. However, the 5-year survival rate sharply drops to 24% for distant stage disease in which the cancer has metastasized (12). As of January 2012, there were 2.9 million women with a history of breast cancer living in the United States (111).

The following section reviews the association between demographic factors and survival rates. Survival is largely related to stage of disease at diagnosis and tumor size (12). Additional factors related to survival of breast cancer include age at diagnosis (i.e., younger age at diagnosis is associated with lower survival rates), socioeconomic status (i.e., lower socioeconomic status is associated with poorer outcome), and race (i.e., lower survival rate for African American women than Caucasian women) (11; 111). Young breast cancer patients (i.e., diagnosed at age 40 or younger) present with differing tumor biology (e.g., lower rates of *in situ* cancer, higher histological grade, increased risk of

estrogen receptor or progesterone receptor negative diagnoses), which is believed to result in worse clinical outcomes (e.g., higher rate of local recurrences, lower 5-year survival rate) than older cancer patients (158). Breast cancer in young women is a heterogeneous type of breast cancer. African American women under the age of 35 are at increased risk for breast cancer (8; 64; 158). African American women also suffer from a more aggressive type of breast cancer that is diagnosed at later stages. Among African American women, between the years of 2001 and 2010 mortality rates have decreased annually by 1.6% (11). Breast cancer deaths have also declined each year (i.e., 2001-2010) in non-Hispanic whites (1.8%), Hispanics/Latinas (1.7%), and Asian/Pacific Islanders (1.0%).

BREAST CANCER MARKERS

The following section provides an overview of diagnostic breast cancer markers including the stages of breast cancer, histological grade, and tumor markers to convey that breast cancer is a distinct disease with many clinical presentations.

Stage

Breast cancer diagnosis is classified according to stages, which range from stage 0 to stage IV (126; 278). Stage 0, or carcinoma *in situ*, includes two classifications: ductal carcinoma *in situ* and lobular carcinoma *in situ*. Ductal carcinoma *in situ*, which is noninvasive, is a result of abnormal cells solely collecting in the breast duct lining. It is possible that the cancer will advance to invasive cancer as cancer cells spread to other tissues. In lobular carcinoma *in situ*, the lobules of the breast contain abnormal cells (i.e., small cells with round or oval nuclei and small nucleoli that are not attached to each

other) (236). It is rare for this type of cancer to progress to invasive cancer. However, a history of lobular carcinoma *in situ* increases the risk of invasive cancer in the future.

Stage I is further divided into Stages I A and Stage IB (126; 278). The tumor in Stage IA is < 2 cm and is contained within the breast. In stage IA small clusters of cancer cells (0.2 mm – 2 mm) accumulate in the lymph nodes without the presentation of a tumor in the breast. Stage IB also may present as a tumor < 2 cm in diameter with small clusters of cancer cells (0.2 mm – 2 mm) in the lymph nodes. A diagnosis of Stage IIA can occur under three conditions: (1) Cancer cells appear in the axillary lymph nodes with the absence of a tumor in the breast; (2) The presence of a tumor ≤ 2 cm in the breast with evidence of disease in the axillary lymph nodes; (3) 2 cm – 5 cm diameter tumor with no evidence of disease in the axillary lymph nodes. In stage IIB a tumor is present, which is either 2 cm – 5 cm in diameter with presence in the axillary lymph nodes or > 5 cm in diameter but without presence in the axillay lymph nodes.

Stage III is further categorized as Stage IIIA, IIIB, and IIIC (126; 278). A diagnosis of Stage IIIA can occur under multiple conditions. Cancer can be present in axillary lymph nodes that are attached to other structures or cancer is present in the lymph nodes or situated next to the breastbone. No tumor or a tumor up to 5 cm is situated in the breast. In Stage IIIB a tumor of any size is found. Additionally, a tumor has spread to the breast's skin or the chest wall. Cancer can be present in axillary lymph nodes that are attached to other structures or cancer is present in the lymph nodes or situated next to the breastbone. Stage IIIC includes the markers of Stage IIIB, in addition to cancer being present in the lymph nodes superior or inferior to the collarbone and the cancer might appear in the axillary lymph nodes or the lymph nodes closest to the

breastbone. If the lymph nodes have spread above the collarbone, then the cancer is considered inoperable. In Stage IV, metastatic breast cancer, the cancer has spread to distal organs such as the lungs, liver, or brain.

Histological grade

Histological grade consists of the tumor's biological characteristics and applies to invasive breast cancer (303). The histological grade is dependent upon growth patterns and the degree of differentiation of the breast epithelial cells and tumor tissue. The three morphological characteristics are degree of gland or tubule formation, nuclear pleomorphism, and mitotic count. The histological grade is reported as grades 1-3 using the Nottingham Grading System (160).

Tumor markers

The American Society of Clinical Oncology conducted a systematic search of the scientific literature concerning tumor markers in breast cancer (189). The review identified 13 breast tumor markers that currently have or in the future may have clinical utility. Among those tumor markers that currently have clinical utility are estrogen receptors, progesterone receptors, and human epidermal growth factor receptor (HER2). Concerning estrogen and progesterone receptors, the identification of these markers suggests that additional hormone therapy is appropriate. HER2 over expression and amplification indicates poorer prognosis. The presence of HER2 status determines that a breast cancer patient should receive specific chemotherapeutic agents or adjuvant therapy (e.g., trastuzumab).

TREATMENT

The following section reviews cancer treatment for breast cancer. Treatment factors have been associated with late and long-term effects of cancer (165); however, these research findings are inconsistent. A large sub-set of breast cancer survivors continues adjuvant therapy for many years following the completion of primary treatment. Therefore, a proportion of the current study's sample will likely be taking adjuvant therapy.

Stage of disease, histology of the tumor, lymph node status, HER2, hormone-receptor status, age of the patient, menopausal status, patient preferences, and the risk and benefits associated with the treatment modality determine treatment received (9; 65). Surgical as well as adjuvant therapies are considered when treating breast cancer. Local disease (cancer confined to the breast) is typically treated with surgery, radiation therapy, or both. Systemic disease is treated with a combination of endocrine therapy, chemotherapy, and/or biological therapy.

In pure noninvasive carcinomas, lobular carcinoma *in situ*, and ductal carcinoma *in situ* (Stage 0), following bilateral diagnostic mammography imaging, treatment focuses on clinical observation and node dissection (65). However, under certain circumstances (e.g., if there is a strong family history of breast cancer or the patient has a BRCA1/2 mutation, which is a mutation in tumor suppression genes) more invasive treatment including lumpectomy or mastectomy may be recommended. With diagnoses of invasive breast cancers Stages 1, IIA, or IIB, it is advised that breast cancer patients receive breast conserving surgeries (i.e., lumpectomy, axillary dissection, whole breast irradiation), radiation therapy, and preoperative chemotherapy (i.e., for Stages IIA and IIB). Depending on the patient's age (i.e., if under age 70), systemic adjuvant therapy

following surgery is typical. For patients who are ER- or PR- positive, adjuvant endocrine therapy is advised (65). When considering inoperable Stage III, standard treatment begins with anthracycline-based preoperative chemotherapy followed by either total mastectomy with level I/II axillary lymph node dissection or lumpectomy with level I/II axillary dissection. Radiation is advised when internal mammary lymph nodes are affected (306). Adjuvant therapy and endocrine therapy is recommended for patients with hormone receptor-positive disease (65). Treatments for Stage IV metastatic cancer prolong survival but are not curative. Therefore, it is recommended to treat with minimally toxic endocrine therapies as compared to cytotoxic therapy, when possible. The National Comprehensive Cancer Network suggests considering surgery following initial systemic treatment if the primary tumor is intact. Radiation therapy can also be considered as an alternative to surgery (65).

Surgery

Independent of the type of surgery, the primary purpose of surgery is to excise the cancer from the breast (9). A simple or total mastectomy involves the removal of the entire breast, whereas modified radical mastectomy removes the entire breast including the lymph nodes below the arm. The underlying chest wall muscle stays intact. The breast cancer patient is provided the option of breast reconstruction surgery, which can be performed following the mastectomy. Alternatively, a lumpectomy removes the cancerous tissue as well as a rim of normal tissue. A 20-year longitudinal, randomized control trial (N = 1,800) that compared lumpectomy plus radiation to mastectomy for invasive breast cancer indicated no difference in survival (146).

Regardless of the type of surgery it is routine for the surgeon to excise regional lymph nodes in the axilla (9). This procedure allows the pathologist to determine whether the cancer has spread and if additional treatment than initially planned is necessary. Lymphedema, or the retention of lymph fluid resulting in the swelling of the arm, can be both a long-term or late effect of radiation therapy with axillary nodes (49). Sentinel lymph node biopsy, a sampling of lymph nodes for testing of lymph node enlargement, prior to surgery determines whether complete axillary lymph node dissection is necessary. This procedure reduces the likelihood of lymphedema (373).

Radiation therapy

Radiation therapy can be used both prior to surgery or following surgery (65). When used prior to surgery, its purpose is to shrink the tumor. When used following surgery, the purpose of radiation therapy is to eradicate cancer cells that are still in the breast, chest wall, or beneath the arm (125). Breast cancer patients typically receive external beam radiation, which involves a machine targeting the breast with radiation outside the body. The typical course of external beam radiation lasts for five to seven weeks, with five weeks of daily therapy to the whole breast followed by one to two weeks of therapy to the tumor bed (i.e., tissue where the tumor is located) (374). Some breast cancer patients also receive internal radiation therapy that places radioactive substances into or close to the cancer. This treatment can be in conjunction with or independent of external beam radiation (9). When given post-operatively, administering chemotherapy before radiotherapy results in an increased chance of survival (305).

Systemic therapy

Biologic therapy, chemotherapy, and hormone therapy are all forms of systemic therapy, or anti-cancer drugs, that are administered orally or injected into the vein and which travel through the bloodstream (11). Systemic treatment can be administered prior to surgery (i.e., neoadjuvant therapy) or following surgery (adjuvant therapy) (252). Neoadjuvant therapy is administered to reduce the size of the tumor allowing for surgical removal. Its administration requires a less invasive surgery. Adjuvant therapy is designed to eradicate undetected cancer cells following surgery. The decision to use adjuvant therapy is based on histology, tumor size, and whether cancer is present in the axillary nodes (9). Mauri and colleagues conducted a meta-analysis to examine differences between clinical outcomes for neo-adjuvant and adjuvant therapies (252). The analysis indicated no statistical or clinical significant differences between neo-adjuvant and adjuvant therapies as related to death, disease progression, or distant disease recurrence. Patients who received neo-adjuvant therapy had an increased risk of loco-regional disease recurrences.

Studies have concluded that a combination of chemotherapeutic agents is advisable when treating breast cancer (210). However, the optimal combination has yet to be determined (253). Results from studies suggest that chemotherapy administered for four to six months leads to better outcome than chemotherapy administered for less than three months (210). The drugs are administered in cycles that last three to four weeks at a time. Common chemotherapy drugs include cyclophsophamide, fluorouracil, methotrexate, epirubicin, doxorubicin, and paclitaxel.

Hormone therapy is appropriate for breast cancer patients whose tumors are estrogen receptor positive (11). Estrogen facilitates the growth of breast cancer and

hormone therapy impedes this process. One common hormone therapy is tamoxifen, a selective estrogen receptor modulator. Tamoxifen is prescribed to premenopausal and postmenopausal women. Aromatase inhibitors (e.g., letrozole, anastrozole, and exemestane) are also becoming more frequent for postmenopausal breast cancer patients (201). In postmenopausal women, aromatase inhibitors block an enzyme that produces estrogen. Aromatase inhibitors are ineffective for premenopausal women because they do not influence the ovaries, which also produce estrogen. A meta-analysis indicated decreased cancer recurrence were greater with aromatase inhibitors than tamoxifen (118). Biologic therapy is included in the treatment plan for HER2/*neu* breast cancers, which is present in 15% to 30% of all breast cancer cases (9). Hormone therapy is prescribed for many years following the completion of primary treatment. For instance, adjuvant therapy (e.g., tamoxifen) is typically prescribed for a 5-year duration post-primary treatment (118; 391). Therefore, participants in the current study will likely be prescribed adjuvant therapy to prevent a tumor recurrence.

PHASES OF CANCER

Breast cancer is a chronic disease and the point at which an individual is on the trajectory, or specific phase of cancer, influences her overall function, well-being, and health care service needs. Therefore, the following section reviews the historical and current views of the distinct phases of cancer. Conceptualizations of the phases of cancer care and cancer survivorship have evolved over the past few decades. In 1985, Mullan, a physician reflecting on his own experience with cancer, described three seasons of cancer survival (i.e., acute survival, extended survival, and permanent survival) (274). Acute survival commences at diagnosis and continues through primary treatment. The

transition into extended survival occurs upon the onset of remission. During extended survival intermittent treatment may be necessary. Physical and emotional limitations related to cancer and cancer treatments are noted. "Permanent survival," which Mullan described as being likened to a "cure" represents the final phase of cancer survival. During this phase there is low risk of a cancer recurrence. Currently, this phase resembles when providers indicate patients have *no evidence of disease*. It is a time when cancer survivors have finished primary treatment, but continue to be affected by co-morbidities of the disease. The late and long-term effects of the cancer and its treatment pose a risk to the cancer survivor's daily functioning, health, and overall well-being. In 2005, the Institute of Medicine declared that cancer survivorship is a distinct phase of cancer care (216). This phase begins after the completion of acute treatment (e.g., chemotherapy, radiation, surgery). The focus of this phase of cancer is to manage chronic or intermittent co-morbidities (medical, psychological, behavior related) and to provide surveillance for recurrence or second cancers (216). **The Cancer Survivor Profile (CSPro) will be integrated into the more recent view of cancer survivorship as a distinct phase of cancer care**.

MODELS OF FOLLOW-UP CARE

The following section provides an overview of different models of follow-up cancer survivorship care that have been proposed in the scientific literature. The type of model implemented in a care setting influences which type of health provider is responsible for the administration and use of the CSPro. There are multiple proposed models to deliver care during the cancer survivorship phase of cancer care. The shared-care model of follow-up care combines the efforts of the oncologist and the primary care

provider (216). At time of diagnosis the oncologist assumes the primary medical role for the individual. One to two years after treatment, primary care transitions back to the primary care provider who addresses the cancer survivor's physical, emotional, cognitive, behavioral, and functional needs (288). A cancer-related summary (e.g., Survivorship Care Plan, treatment summary) should guide the primary care providers' treatment of the survivors' cancer-related concerns. The oncologist continues to address specific cancer-related problems and conducts periodic evaluations. Frequent communication and shared expectations between the oncologist and primary care provider is needed (288).

While primary care providers express a strong interest to assume an active treatment role for cancer survivors (80), several barriers to this model are evident. Primary care providers indicate that they do not have adequate training to evaluate and treat cancer-related sequelae (222; 284). In a sample of 587 primary care providers, about 25% of the sample reported low confidence providing counseling for sexual function and body issues (336). Also, as the incidence of breast cancer rises and the mortality rates due to cancer decrease, the prevalence of breast cancer survivors will increase. Statistical projections indicate that there will be a shortage of primary care providers and oncologists by 2020 (128; 346). Therefore, it may not be practical for oncologists and primary care physicians to assume the principal role for treating and following the cancer survivor, especially for non-medical needs (e.g., mood disorders) that can be addressed by other specialists.

The nurse-led model of cancer follow-up care represents another option for cancer survivorship care. Nurses have successfully coordinated and provided follow-up care for childhood cancer survivors (204) and cancer survivors in rural settings (387). A review

of the literature indicated that nurse led telephone follow-up services were an effective way to provide informational and psychological support (e.g., assisted with cancer-related factors such as management of symptoms) to cancer survivors (99). In a discussion on nurse-led follow-up care, the Institute of Medicine suggested that specialist nurses have the appropriate education and training in symptom management, psychosocial care, patient assessment, and care planning (216). However, oncology nurses are primarily in hospital settings rather than outpatient or community-based settings. This factor represents a barrier to nurse led follow-up care because the care is most likely to be conducted from outpatient or community-based settings (216). Training primary care nurses to deliver survivorship care is a potential solution to this barrier.

Survivorship follow-up clinics represent a third option for cancer follow-up care (216). National Cancer Institute designated cancer clinics are now a part of 27 hospitals (279). Additionally, there are 42 comprehensive cancer centers in the United States. These clinics specialize in cancer survivorship follow-up care. However, there are limitations in the current practice of cancer specific care centers. For example, LIVESTRONG™ Network of Survivorship Centers do not provide care in agreement with the Institute of Medicine's recommendations for treatment summaries (i.e., record of chemotherapy, radiation, surgeries, and hormonal therapy received) and Survivorship Care Plans (349). Certain concerns were more strongly emphasized (e.g., potential toxicities, late effects) than others (e.g., psychosocial concerns, prevention/health promotion recommendations) in the follow-up care. While there has been discussion about survivorship follow-up clinics within the scientific literature, there are multiple barriers to survivorship follow-up clinics' ability to provide services effectively. These

clinics are labor intensive, costly to run, and not all insurance companies reimburse for their services (62; 216). The separation between the cancer care and other medical issues is so distinct, that coordination and communication among medical providers within the clinics and outside the clinics is difficult (216). **The CSPro may help improve this communication**.

Biopsychosocial Model of Cancer Survivorship

Feuerstein developed the Biospychosocial Model of Cancer Survivorship that illustrates the dynamic interaction among medical (e.g., tumor biology, health status, residual symptoms, medical care), sociocultural (e.g., age, gender, ethnicity, education, socioeconomic status), individual (e.g., coping response, health behaviors, disposition, transformative coping), and environmental factors (geographic, work, family, social support) across the stages of cancer (i.e., diagnosis, treatment, acute, sub-acute, chronic, and end stage) (Figure 1) (140). Whether the individual has recently been diagnosed with cancer, in primary treatment, post-primary treatment, or in the end stage of life, his or her function and well-being is the product of the four main categories. The model focuses on the interplay between biological, psychological, environmental, and sociocultural factors. Also, it recognizes that cancer is not static. An individual may transition between cancer patient and survivor (i.e., due to cancer recurrence or development of new cancers). This transition affects the bi-directional interaction among the four main factors, which results in the individual's functional state and well-being.

CANCER AS A CHRONIC ILLNESS

Breast cancer is viewed as a chronic illness (142). The following section reviews conceptualizations of chronic illnesses, as well as a model that has been proposed to

improve quality care of individuals with chronic illnesses. In 1946 the World Health Organization defined health as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" (392). The World Health Organization's definition of health has a direct impact on the care of cancer survivors. Cancer survivor's health is not merely represented by the absence of the cancer (i.e., disease). For a large sub-set of cancer survivors, problems with physical, mental, and social well-being continue to occur years after the completion of primary treatment (190). Addressing these areas is necessary to promote a state of complete health. Historically, the healthcare system was designed to treat acute conditions (215; 378). Chronic conditions and their associated symptoms were not addressed. Instead, acute conditions typically took priority during a brief appointment with a physician. However, chronic illnesses (e.g., cancer, heart disease, diabetes) affect many individuals and accounts for a large proportion of health expenditures. For instance, among Medicare beneficiaries, 50.2% received treatment for at least five chronic conditions (362). However, these individuals accounted for 76.3% of Medicare expenditures.

Considering the World Health Organization's conceptualization of health (392), following the eradication of disease new problems arise and persist. These problems transition an illness into a chronic condition. For example, after the completion of primary treatment, breast cancer survivors experience problems such as fatigue, pain, sexual dysfunction, and anxiety that continue for many years (190). The purpose of the CSPro is to detect and subsequently direct survivors to appropriate treatment for chronic symptoms of breast cancer.

Wagner developed the Chronic Care Model to improve the care of individuals with chronic medical conditions (37; 38; 377). It was initially designed for the treatment of patients in primary care settings (37), but has been expanded to settings in which cancer patients and survivors are treated (255). The Chronic Care Model considers care for chronic illness to occur in three connected venues. It includes the community (public and private policies, resources), the health care system, and the provider organization (integrated, multidisciplinary, or a small clinic) (37). The coordination of care among the community, health care system, and provider organization can be complicated.

The Chronic Care Model (Figure 2) is consistent with the Institute of Medicine's recommendations to improve the quality of the health system. These recommendations include an ongoing relationship with the medical team, individual care based on the patient's needs, anticipation of the patient's needs, evidence-based practice, and cooperation among providers. The Chronic Care Model proposes a collaborative professional relationship between knowledgeable providers and active patients. This collaboration should incorporate the identification and review of clinical information about the course and management of problems, the setting of goals and the solving of problems, clinical and behavioral interventions, and follow-up care.

To aid in the collaborative professional relationship between patient and provider, the Chronic Care Model is composed of six elements: health care organization, community resources, self-management support, delivery system design, decision support, and clinical information system (37). Health care organization includes the leader. The leader is the individual who is responsible for obtaining resources and removing barriers to care. The leader's goals and values are considered integral to this

element. If the leader does not consider chronic illness care a main concern, then effective care will not take place. Community resources refer to the health care professionals establishing connections with outside organizations to provide additional services to meet patient needs (e.g., exercise programs, support groups). Self-management support assists patients with the development of confidence and skills to manage problems such as the implementation of protective health behaviors and compensatory strategies for poor cognitive function. Self-management can occur through patient activation. More specifically, the provider must work with the patient to develop the confidence and the knowledge to manage components of the chronic illness (e.g., through the implementation of diet and exercise). Delivery system design refers to the organized approach where the provider collects and reviews patient problem information. The provider offers the patient support to change. The provider then follows up with the patient to assess whether change has been made. If proper change has not been implemented, then there is additional adjustment to the plan to better allow for the necessary change. The treatment team consists of different members who intervene on various levels to collect and review patient problem information. The health care providers may treat the acute and chronic issues, where other team members assist the patient to self-manage symptoms. Decision support is the implementation of evidence-based clinical practice guidelines. Finally, the clinical information system is designed to expand the traditional face-to-face visit. It modernizes health care with instruments such as email communication between patient and provider. It also includes a system to aid health care professionals with the compliance of evidence-based practice guidelines, feedback to health care professionals about their management of the chronic illness, and

registries to plan for individual care and perform population-based care. Electronic medical records are integral to the implementation of clinical information systems.

The Chronic Care Model has been applied to the treatment and management of diabetes mellitus (38). A review of 39 intervention studies indicated that 32 of the 39 interventions resulted in the improvement of at least one process outcome measure (i.e., self-management, decision support, delivery system design, or clinical information systems) (38). Health organization and community resources, elements of the Chronic Care Model, were not examined in the review. The review noted whether there were improvements in process of care (e.g., measurement of urine albumin) and/or patient outcomes (e.g., endocrine complications). Bodenheimer and colleagues were unable to conclude whether greater number of components implemented resulted in more effective medical treatment (38). While the studies that included all four components under review found improvements in patient outcomes, studies that only included one component also indicated improvements in patient outcomes. The authors could not conclude whether one component was more effective than another component, but did find that 19 of the 20 studies that included self-management resulted in improved process or patient outcomes. Also, the review examined whether the implementation of the Chronic Care Model reduced costs for patients with diagnoses of congestive heart failure, asthma, and diabetes. The majority of the studies (18 out of 27) found that treating patients within the framework of the Chronic Care Model resulted in reduced health care use and lower health care costs.

A meta-analysis of the Chronic Care Model examined 112 studies (27 on asthma, 21 on congestive heart failure, 33 on depression, and 31 on diabetes) that included a

minimum of one component of the model (365). As in the Bodenheimer and colleagues review (38), this meta-analysis also found that the inclusion of at least one Chronic Care Model component was beneficial to clinical outcomes (e.g., depression) and process of care (e.g., receipt of prescriptions). Self-management was the most common element implemented (80/112 studies). Delivery system design, decision support, clinical information systems, and self-management were associated with improved clinical outcomes and process of care. Similar to the Bodenheimer et al. review (38), it was infrequent for studies to include multiple components of the model. Nearly half of the studies included only one component of the model. However, Tsai and colleagues found that the number of components implemented was not associated with improved outcomes (365). Cancer diagnoses, as a whole, are a distinct chronic illness. However, there are similarities between cancers and other chronic illnesses (e.g., diabetes, asthma, congestive heart failure). Because the scientific community has gained much knowledge about the management of other chronic illnesses, the cancer survivorship field can extract findings from these fields into the management of cancer as a chronic illness (142).

The Institute of Medicine defined self-management in its report, *Priority areas for national action: Transforming health care quality*, as "the systematic provision of education and supportive interventions by health care staff to increase patients' skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting and problem-solving support" p. 57 (2). Self-management of a chronic disease includes initiation and continuation of proper health behaviors, communication with health providers and treatment compliance, patient monitoring of physical and emotional symptoms, and patient management of illness's interference with

functional and interpersonal roles (84). These components of self-management may benefit from the support of a health provider.

Healthcare reform is difficult and it can be financially demanding. Therefore, it may be appropriate to implement only certain components of the Chronic Care Model, especially in primary care practices or smaller medical practices (38). Considering oncology within the context of the Chronic Care Model, self-management of the illness's symptoms (e.g., fatigue, pain) is essential (255). In the United Kingdom there have been efforts to apply the Expert Patients Program, a public health policy initiative, which educates cancer survivors about self-care and self-management (389). Many LIVESTRONG Survivorship Center of Excellence Network sites incorporate patient educational programs into their centers, but do not use interventions that educate patients on self-management of cancer-related symptoms (62).

Self-management for cancer and its associated symptoms requires problem solving, decision-making, communication and partnership among patient and health care providers, resource utilization, and self-tailoring (244). The evaluation and monitoring of the problem is necessary for self-management of the problem (e.g., goal-setting, decision-making, self-monitoring) to occur (322). Detection of the problems is needed prior to the self-management of the problems. Generally speaking, within the field of cancer survivorship problems that merit self-monitoring (e.g., weight management, interpersonal problems) are not discussed in physician visits (222). Health professionals need the proper tools and education to assist cancer survivors with problems and the self-management of these problems. There are many long-term and late effects of breast cancer that health providers need to properly screen for and assist survivors to self-

manage. **The CSPro will assist healthcare providers and breast cancer survivors with the evaluation and monitoring of problems**.

Long-Term and Late Effects of Breast Cancer

The following section reviews the long-term and late effects of breast cancer to provide an overview of the type of problems that healthcare providers need to evaluate and treat. Because the **CSPro will be specific to breast cancer**, studies that examine this population of survivors are reviewed. Some studies examine a heterogeneous group of cancer survivors. However, only those studies that include breast cancer survivors in the sample are included in the review.

SYMPTOM BURDEN

The completion of primary treatment can be a difficult period of time for breast cancer survivors, which is consistent with the noted increased risk for depressive symptoms, anxiety symptoms, and poor quality life (92). Psychosocial problems are heightened in breast cancer survivors compared to woman with no history of cancer (190). The unexpected occurrences of long-term (i.e., originate during treatment and persist into survivorship) and late effects (i.e., originate any time point post-primary treatment) of cancer can intensify anxiety and depressive symptoms in breast cancer survivors (318). In a heterogeneous sample of 1,111 cancer survivors who were at a minimum 5 years post-diagnosis and 4,444 matched controls, the cancer survivors were more likely to have a mental health diagnosis (e.g., anxiety, sleep disorder) (124). Of all cancer survivors sampled, the prevalence of mental health disorders (e.g., major affective disorder) was highest among the breast cancer survivors. The prevalence of major depressive disorders varies depending on a study's methodology. Estimates as high as

22% of breast cancer survivors (on average 4 years post-diagnosis) with a major depressive disorder diagnosis has been documented when using self-report measures of depression (256). Because symptoms can occur at many time points post-primary treatment for breast cancer (318), continual monitoring for detection and management of the symptoms is a necessity. For instance, depression may not be experienced until 6 months or more following treatment completion (112). Other breast cancer survivors may vacillate between meeting criteria for depression and not having a clinical diagnosis of depression. Breast cancer survivors who do not meet the criteria for major depressive disorder may still experience symptoms of depression at sub-clinical levels, which interfere with daily functioning (78). A systematic review indicated that 15-32% of breast cancer survivors reported depressive symptoms 2 to 5 years following the completion of primary cancer treatment (190).

Fatigue is a persistent problem for many breast cancer survivors initially occurring during primary treatment and extending many years post-treatment (42). As the most common symptom following breast cancer, fatigue affects about a third of breast cancer survivors at 3 years (43) and 10 years (42) after completion of primary treatment. Because of the comorbidity of fatigue with other long-term symptoms of cancer, including depression, a careful assessment for diagnosis and treatment with validated tools is necessary. Significant elevations of anxiety consistent with diagnostic criteria for an anxiety disorder were observed in 9.4% of breast cancer survivors 2 to 10 years post-diagnosis relative to individuals with no history of cancer (206). Not surprisingly, many cancer survivors experience cancer-related worry (137). Breast cancer survivors report concern about cancer recurrence and health problems related to cancer treatment (271).

Even 5 years post-cancer, 70% of breast cancer survivors fear recurrence, which intensifies emotional distress (250).

Pain is a persistent problem among breast cancer survivors. Researchers in Denmark conducted a nationwide cross-sectional study to investigate persistent pain 2 to 3 years after surgical treatment for breast cancer (N = 3253) (168). Forty-seven percent of the breast cancer survivors reported pain in the surgical site, among which 13% indicated severe pain, 39% moderate pain, and 48% light pain. Age group 18-39 (odds ratio = 3.62; 95% confidence interval, 2.25-5.82, $p < 0.001$), axillary lymph node dissection (odds ratio = 1.77, 95% confidence interval = 1.43-2.19, $p < 0.001$), and adjuvant radiotherapy (odds ratio = 1.50, 95% confidence interval = 1.08 to 2.07, $p = 0.03$) were associated with pain. Chemotherapy was not associated with chronic pain. Within the total sample, 40% also reported pain in non-surgical sites (e.g., low back pain, headache). Only 20% of breast cancer survivors who reported pain indicated that they contacted their physician in the last 3 months concerning the pain. A longitudinal study on pain and breast cancer assessed pain in breast cancer survivors (N = 3088) on average 2 years post-diagnosis and 70% of that sample 4 years later (n = 2160) (312). Breast cancer survivors reported a significant increase in pain 4 years post-diagnosis. An increase in pain was positively associated with medical variables (surgery, tamoxifen use at baseline) and positively associated with psychological factors (reports of depression or stressful life events at baseline). Breast cancer survivors who reported that they exercised at baseline also reported significantly less pain 4 years post-diagnosis.

Breast cancer survivors also experience physical and emotional symptoms related to cancer and its treatment. Treatment-related factors can negatively impact body

structure and reproductive function. In the first 7 months following the completion of primary treatment, about 50% of survivors experienced body image concerns, which were positively associated with mastectomy, weight gain, hair loss, lower self-esteem, and the survivor's partner not understanding the survivor's feelings (151). Dissatisfaction with weight gain and body image were independent of age in breast cancer survivors (166). Treatment-related fertility problems also negatively affected breast cancer survivors' overall health self-perception (166). Pre-menopausal breast cancer survivors 1 year post-diagnosis reported significantly greater fertility concerns (80%) than age- and gravidity-matched controls (25%) (321). In women who were pre-menopausal at diagnosis (age 40 and below), reproductive concerns were predictive of depressive symptoms on average 12 years post-diagnosis (174). In a large sample (N=577) of breast cancer survivors ages 30 to 61.6, only 5% of women reported a successful pregnancy following diagnosis despite 20% of women planning to have children prior to their diagnosis (166). Breast cancer survivors indicated that when deciding whether to have children following cancer, their physician's recommendations about pregnancy, worry regarding risk, age, and "personal relationship situation" influenced their decision (166). Pre-menopausal breast cancer patients indicated a need to receive a consultation with a fertility specialist to obtain information on and discuss fertility options (292).

Some cancer survivors may experience a higher level of overall symptoms, or symptom clusters, than other cancer survivors. A study of heterogeneous cancer survivors (N = 4903) reported that 92% (n = 4512) experienced symptoms (e.g., pain, depression, fatigue, confusion) related to cancer (330). A 2-step clustering analysis

divided survivors into a low symptom burden group (n = 3113) and a high symptom burden group (n = 1399). Lung cancer, metastatic cancer, younger age, number of comorbid conditions, receiving active chemotherapy, lack of insurance/being uninsured, lower income, unemployment, and less education were associated with the high symptom burden cluster. Depression, fatigue, and pain had the largest negative impact on cancer survivors health related quality of life. **The CSPro has the potential to monitor seven different symptoms.** Considering the work of Shi and colleagues (330), a sub-set of breast cancer survivors may endorse more symptoms at increased intensity than other breast cancer survivors.

FUNCTION

Cancer also can negatively impact function including work ability, cognitive function, sexual function, sleep, and social relationships. Cancer survivors have expressed a desire to return to and remain at work following cancer (223). However, a meta-analysis on cancer diagnosis and unemployment indicated that breast cancer survivors (33.8%) had a higher rate of unemployment than controls (15.2%; pooled relative risk = 1.37, 95% confidence interval = 1.21-1.55) (107). A review of the literature indicated that limitations in cognitive functioning (e.g., attention, learning, memory, processing speed, and executive function) were documented in 13 to 34% of breast cancer survivors when comparing cognitive function pre-cancer treatment to post-cancer treatment (383). Calvio and colleagues found that performance-based neuropsychological measures did not detect cognitive deficits in breast cancer survivors, despite survivors' self-reported cognitive and work limitations (58). Furthermore, Ferguson and colleagues investigated cognitive function in a pair of monozygotic twins

(135). One twin had a history of breast cancer and exposure to chemotherapy, whereas the other twin had no history of cancer or exposure to cancer treatment. There were no significant differences between the twins on neuropsychological tests. However, the twin with a history of breast cancer reported significantly greater cognitive complaints. Also, functional magnetic resonance imaging revealed more white matter hyperintensities in the twin who had a history of breast cancer. While functional magnetic resonance imaging may be impractical for everyday tests of cognitive problems, completion of self-report self-measures is not. These findings suggest that self-report cognitive function outcomes are a useful tool to assess cognitive problems.

A systematic review of long-term and late effects of cancer identified six studies that investigated sexual dysfunction among breast cancer survivors (190). Five of the six studies found sexual dysfunction to occur among breast cancer survivors (e.g., vaginal dryness, dyspareunia, and decreased sexual desire) from completion of primary treatment to more than 5 years post-treatment. One study included in the review indicated that 51% of breast cancer survivors reported sexual dysfunction 1 to 2 years post-treatment. The percentage declined to 28% 2 to 5 years post-treatment. Moreover, another study, not included in the systematic review, indicated that cancer survivors were at greater risk for sleep disturbance than were individuals with no history of cancer (1.5 verses 0.7%, $p = 0.01$) (124). Poor sleep has been positively associated with fatigue and depressive symptoms (67).

There is mixed support concerning the negative effect of poor social relationships on breast-cancer specific mortality (25; 232; 381). However, there is some evidence that social relationships are positively associated with breast cancer survival among women

diagnosed with primary ductal breast cancer (381). In a prospective study of 133 breast cancer patients from time of diagnosis to 4 years post-diagnosis, Waxler-Morrison and colleagues found that marital status (i.e., being married), support from friends, contact with friends, social network, employment status, and total support (friends, relatives, neighbors) were positively associated with survival (381). In qualitative interviews with a sample of the breast cancer survivors, the breast cancer survivors described the importance of social relationships. Breast cancer survivors reported that while tangible support ("having a shoulder to cry on") was important, that "practical" or "concrete" support (e.g., transportation to the hospital, child care, cooking) was more helpful. While Beasley and colleagues did not find an association between social networks and breast cancer specific mortality (25), this study along with Kroenke and colleagues' study (232) found that the lack of social relationships was positively associated with all-cause mortality. Similar to Waxler-Morrison et al., (381) Kroenke and colleagues (232) found that breast cancer survivors who were socially isolated had an increased risk of breast cancer mortality (HR = 2.14; 95% Confidence Interval, 1.11 to 4.12). Despite the mixed results concerning social relationships impact on cancer survival, research suggests that social relationships provide a positive benefit to breast cancer survivors (326). Engagement in relationships that provided emotional support was positively associated with positive posttraumatic growth from cancer ($r = 0.29$, $p < 0.001$) (326). Considering the positive effects that social relationships have on cancer survivors, it is important to monitor these relationships in breast cancer survivors. Breast cancer survivors who report poor social relationships may benefit from an intervention to improve their social

relationships. Therefore, **the CSPro will evaluate social relationships** in breast cancer survivors.

HEALTH BEHAVIORS

Poor health behaviors pose a risk to a breast cancer survivor's well-being. Health care providers can assist breast cancer survivors with incorporating preventive health behaviors into their everyday lives. Therefore, the CSPro will evaluate preventive health behaviors. While behavior change is difficult, it can pose an increased challenge for breast cancer patients and survivors because of cancer's late and long-term effects (e.g., fatigue interfering with exercise) (95; 315). However, breast cancer survivors incorporating proper health behaviors into their lives is critical. Poor health behaviors (e.g., alcohol consumption ≥ 6 g/day, poor nutrition, lack of physical activity) have been positively associated with an elevated risk for recurrence, secondary cancers, and other chronic illnesses (82; 119; 233). Exercise can increase the longevity of a breast cancer survivor. A prospective observational study that investigated nurses (N = 2,987) diagnosed with breast cancer from 1984-1998 until June 2002 or death found that exercise (≥ 3 metabolic equivalent task hours/week, which amounts to walking at 2 – 2.9 miles per hour for 1 hour) decreased the risk of mortality in breast cancer survivors (208). A longitudinal study that investigated exercise in breast cancer survivors 6, 18, and 36 months post-diagnosis indicated that more exercise (≥ 8.3 metabolic equivalent hours/week) had persistent positive effects on a self-report measure of overall quality of life in breast cancer survivors (79). Consuming a diet low in fat may reduce breast cancer recurrence in post-menopausal breast cancer survivors (82). Despite these findings, inactivity and obesity have been found to be greater in breast cancer survivors

than in matched non-cancer controls (286). In general, cancer survivors were not within the national guidelines for diet and exercise (28; 119).

In a heterogeneous sample of over 1,800 cancer survivors, 80% were non-smokers, 52% engaged in physical activity at a "vigorous" level ≥ 3/week, and 37% maintained a body mass index within normal range. However, only 16.5% of the total sample maintained all three preventative lifestyle behaviors (144). Survivors with a poorer perception of their mental health engaged in fewer preventative lifestyle practices (by 8%) than survivors who endorsed excellent perceived health. Data from this study were derived from the Medical Expenditure Panel Survey, providing a nationally representative sample. Findley and Sambamoorthi reported findings from cancer survivors. No comparison was made with a healthy control group; however, direct comparisons with healthy population based samples are possible (144). The Findley and Sambamoorthi study also did not provide information on type of substance that the smokers used (e.g., cigarettes, cigars) (144).

Providers have the opportunity to play an important role in educating cancer survivors on protective health behaviors. In a heterogeneous group of cancer survivors (N=352), 46% of cigarette smokers quit smoking after diagnosis. However, 43% denied that their physician recommended that they abstain from smoking (33). Alcohol consumption is associated with increased risk of breast cancer and breast cancer related death, with greater risk among post-menopausal, overweight, and obese women (233). Results from randomized control trials provide evidence for a combined individualized counseling and Weight Watchers program for weight loss (114), telephone counseling for dietary habits (294), and physical exercise interventions for cardio respiratory fitness and

vigor (325). The assessment of these health behaviors is a necessary first step prior to a breast cancer survivor's enrollment in a treatment program or for the implementation of self-management strategies. **The CSPro measures protective health behaviors.** The CSPro provides the opportunity for health providers to speak with cancer survivors about the importance of health behaviors, as well as allow for a more intensive intervention if needed.

HEALTH SERVICES

The Institute of Medicine described cancer survivorship as a distinct phase of cancer care (216). However, the continuity and coordination of care is not well established when an individual transitions from cancer patient to cancer survivor. Patients and providers are unsure how to coordinate care post-primary treatment and what symptoms to monitor (122). Qualitative work (i.e., three focus groups with 10-12 participants/group) has highlighted cancer survivors' strong interest to be better educated about caring for themselves and what to expect post-active treatment (196). Even long-term breast cancer survivors (on average 10 years post-diagnosis) reported difficulty understanding medical research concerning cancer (178). These breast cancer survivors were unsure what news stories to trust and whether a finding was scientifically based. Cancer survivors expressed difficulty finding and understanding cancer-related information (254). The majority of cancer survivors preferred to receive cancer-related information from their health care providers (254). However, almost 50% of cancer survivors obtained the information from other sources, such as the Internet and books, despite being concerned about the quality of the information.

Cancer survivors indicated that their psychosocial needs were unmet following cancer (196). There is a potential economic benefit in addressing problems of cancer survivors. Cancer survivors who experienced more psychological problems and/or functional limitations had 34.6% and 18.2% more healthcare visits, respectively, than did cancer survivors with fewer problems (198). Cancer is already known to be a financial burden for survivors, with increased medical costs (e.g., insurance premiums, deductibles, co-payments) and lost income (380). Economic burden may compromise compliance with treatment and patient outcomes (380). Breast cancer survivors with Medicaid or who were uninsured were less likely to receive breast cancer surgical treatment (9.3% and 15.5%, respectively, did not receive treatment) than breast cancer survivors with private insurance or Medicare (4.3% and 8.2%, respectively, did not receive treatment) (87). The study did not adjust for socioeconomic status, race, or other demographic factors. Therefore, caution is needed when interpreting these results.

Breast cancer survivors expressed that they did not report psychosocial problems to their physicians and that their physicians did not ask about their psychosocial problems (222). Some breast cancer survivors did not report symptoms to their physicians because the survivors worried that these reports might be misinterpreted as exaggerations and thereby weaken the doctor-patient relationship (318). It is important for physicians to be aware of all survivor concerns and perceptions about how they present themselves because these concerns and perceptions are currently a barrier to quality care. Research indicated that cancer survivors' satisfaction was positively related to the extent that their physicians discussed treatment outcomes with them (78). However, this association is likely bidirectional.

Currently, there is a discrepancy between physicians and patients, as well as primary care physicians and oncologists, concerning what defines optimal follow-up care for cancer survivors and how to achieve it (81) Regarding psychosocial concerns, less than 10% of oncology-related health care providers who inquired about mood used any type of validated screening tool (264). Providers specified that barriers in screening depression included lack of time, insufficient training, and low confidence about diagnosis. The study identified these oncology-related healthcare providers as doctors and clinical nurse specialists. While not specific to cancer survivors, a recent meta-analysis reported that general practitioners had poor clinical accuracy when identifying patients with mild depression or distress (265). Aside from the impact depression has on daily functioning, depression may increase risk of cancer progression and mortality through dysregulation of the hypothalamic-pituitary-adrenal axis and/or suppressed immune function (203; 342). These findings support the need for healthcare providers to use validated self-report assessments to aid with accurate diagnosis and effective treatment problem areas.

SURVIVOR CARE PLANNING

Over the past decade, Survivorship Care Plans have been proposed as one approach to improve the quality of care cancer survivors receive. The Institute of Medicine recommended Survivorship Care Plans, which provide a comprehensive summary of tumor pathology, treatment exposures, long-term and late effects of cancer and its treatment, health behaviors, and psychosocial concerns (216). It is designed to be individualized and modified based on a survivor's developing concerns, including recommendations for short-term and long-term follow-up needs (167; 215). Multiple

health care providers (e.g., oncologist, primary care physician, nurse) could complete a Survivorship Care Plan with a breast cancer survivor. Cancer survivors express a need for a Survivorship Care Plan (196). Similarly, primary care providers and nurses report that a written Survivorship Care Plan would be helpful to provide quality care (e.g., easing transition into survivorship, proper follow-up care, organization of cancer history that would influence medical care) to cancer survivors (196).

To date only two randomized control trials that investigated the validity of the Survivorship Care Plan have been conducted, one in breast cancer survivors(182) and the other in gynecological cancer survivors (50) In the study of breast cancer survivors, a sample of 408 breast cancer survivors were randomized to either receive the Survivorship Care Plan or to a control group (182). Participants completed primary treatment a minimum of 3 months prior to the study (*Mdn* time since diagnosis = 35.3 months). Regardless of group assignment, participants' follow-up care was transferred to their primary care provider. All participants received a discharge visit with their oncologist. The intervention arm also received the Survivorship Care Plan. These participants reviewed the Survivorship Care Plan with a nurse during a 30-minute educational session. The Survivorship Care Plan consisted of a personalized treatment summary, the Canadian national follow-up guidelines, a summary table of the follow-up guidelines, and a survivor tailored supportive care resource kit. The primary dependent variable was a self-report measure of cancer-related distress (i.e., Impact of Event Scale). The Survivorship Care Plan had no significant effect on patient satisfaction, mood, distress, or continuity and coordination of care over 12-months. The generalizability of these results has been questioned (337). Flaws in the design of the study (e.g., outcome measures)

may account for the results. The Impact of Event Scale is a measure of posttraumatic stress disorder. Brothers and colleagues investigated whether gynecological cancer survivors (n = 121) within one year post primary treatment would evaluate quality of care differently based on whether they received a Survivorship Care Plan or standard treatment (focus on medical examination, recurrence surveillance, treatment related morbidities). Providers were randomized to either the Survivorship Care Plan condition (n = 3) or standard care condition (n = 3), and their patients were then categorized into their providers' intervention arm. Self-reported quality care did not differ between the two groups (64 survivors received plans, 57 did not). The study has limitations that are important to note, including that the study was cross-sectional. That is, survivor rating of quality care was provided immediately after receiving the Survivorship Care Plan. Therefore, there was no opportunity to measure long-term effect on quality care. Also, the study did not report information concerning specialty of physician providing care.

AVAILABLE SELF-REPORT INSTRUMENTS FOR BREAST CANCER SURVIVORS

For many years there was a shortage of instruments to assess psychological constructs in cancer patients. This lack of availability may in part be related to the stigma that was largely associated with cancer (295). However, with the increase in cancer survival, along with formal documentation of psychiatric illnesses in cancer patients (109), researchers began to express concern that the scales used to assess psychosocial constructs in cancer patients were validated in college populations and not medical populations (295). These concerns were addressed in the first conference on psycho-oncology in San Antonio, Texas in 1975 (207). Additionally, foundations such as the American Cancer Society supported research to create measures to assess psychosocial

constructs in cancer patients (207). Over the next several decades researchers developed and validated self-report instruments in cancer patients. However, there are a lack of measures to assess emotional, cognitive, behavioral, functional, and health service concerns in cancer survivors. Many instruments, which are reviewed in Table 1 and below, that were validated in cancer patients are being used with cancer survivors. Yet cancer patients and cancer survivors represent two different stages across the cancer trajectory and present with different problems (216). It is unknown whether scales validated in cancer patients during treatment are applicable to cancer survivors following primary treatment. There are also few self-report measures that were designed for or are appropriate for clinical use (310). Table 1 provides a review of previous measures used with breast cancer survivors. These measures are also reviewed below.

SELF-REPORT MEASURES FOR CANCER PATIENTS

There are self-report measures that were validated for cancer patients but that are used in the cancer survivor population. The Functional Assessment of Cancer Therapy-Breast and the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaires (QLQ-30 and QLQ-BR21) were designed to be outcome measures in oncology clinical trials (40; 47). These measures have been used in breast cancer survivors (133; 191), but they have not been validated for this population. Because they were designed for cancer patients, they do not measure problems specific to or that are more prevalent in cancer survivors (e.g., fear of recurrence, reduced social support). Some of the items are no longer relevant to cancer survivors post-primary treatment (e.g., short-term side effects to primary treatment for cancer such as nausea).

Self-report measures for long-term cancer survivors

In 1997, the National Cancer Institute called for the development of scales to assess problems in long-term cancer survivors (RFA-CA-97-018). Subsequently, self-report instruments specifically for long-term cancer survivors have been developed. The scales measure singular constructs (e.g., quality of life) and appear to be research oriented rather than clinically oriented. More specifically, researchers designed the measures to determine the type of problems long-term cancer survivors experience in research studies. Researches did not conduct studies on the measures' clinical validities. Three out of four measures reviewed in Table 1 were validated on a heterogeneous sample of cancer survivors. For instance, the Quality of Life-Cancer Survivors assesses the physical, psychological, social, and spiritual well-being of a heterogeneous sample of male and female cancer survivors who were on average 6.8 years post-diagnosis (136). Wyatt and Friedman developed the Long-Term Quality of Life instrument (395), using Ferrell's conceptualization of quality of life among cancer survivors. Therefore, it too measures physical, psychological, social, and spiritual quality of life. As noted in Table 1, the Long-Term Quality of Life instrument was validated on female cancer survivors who were at least 5 years post-diagnosis. The authors did not indicate what cancer diagnoses were included in the study's sample.

Zebrack and colleagues developed the Impact of Cancer self-report scale to assess health awareness, health worries, body changes, positive and negative self-evaluation, social life interferences, positive and negative life outlook, and meaning of cancer in breast, prostate, colorectal, and lymphoma cancer survivors (400). The measure was intended to provide a better understanding about the type of problems long-term cancer survivors' experience. The validation study's respondents were on average 7.67 years

post-diagnosis. Crespi and colleagues further refined the Impact of Cancer Scale (Impact of Cancer Scale version 2) to assess long-term breast cancer survivors' quality of life (101). The factors included the Positive Impact Summary scale and the Negative Impact Summary scale. Each contained four sub-scales (Positive Impact Summary: Altruism and Empathy, Health Awareness, Meaning of Cancer, Positive Self-Evaluation; Negative Impact Summary: Appearance Concerns, Body Change Concerns, Life Interferences, Worry). An additional scale was produced through content review and based on the internal consistency reliability of remaining items. This scale, labeled Employment and Relationship Impacts, includes three sub-scales (Employment Concerns, Relationship Concerns [Not Partnered], Relationship Concerns [Partnered]). These self-report measures for long-term cancer survivors may not be appropriate for breast cancer survivors who completed treatment within the past five years. The scales are not specific to the needs of breast cancer. The type of problems that more recent breast cancer survivors experience may be different than the types of problems that longer-term cancer survivors experience. Also, these self-report measures were not validated for clinical use. **The CSPro is designed to fill this gap. It will be specific to breast cancer survivors within the first five years of completion of primary treatment and is intended for clinical use**.

Physical symptoms

Stanton and colleagues developed the Breast Cancer Prevention Trial (BCPT) Symptom Scales, which is a self-report measure of cancer patient's physical symptoms (345). The instrument is used in women with a diagnosis of or who are at risk of breast cancer. Items from the BCPT Symptom Scales were derived from the BCPT Symptom

Checklist. The BCPT Symptom Checklist is a 42-item self-report measure that assesses physical and psychological symptoms associated with cancer treatment. The BCPT Symptom Checklist was constructed using items from questionnaires that examined menopause and tamoxifen related side effects (164). The BCPT Checklist was administered to four samples (Sample 1: Breast cancer survivors stage 0-II; Sample 2: Breast cancer survivors stage 0-II ages 50 or less; Sample 3: Breast cancer stage I-II; Sample 4: At risk for breast cancer [hyperplasia with ataxia, hyperplasia with BRCA1 and/or BRCA2 mutation]). Analyses resulted in the following eight factors: nausea, hot flashes, bladder control, vaginal problems, musculoskeletal pain, cognitive problems, weight problems, and arm problems. **The CSPro is designed to be more comprehensive** than the physical symptoms included in the BCPT Symptom Checklist. **The CSPro also includes domains (i.e., symptom burden, function, preventative health behaviors, and health service needs) that are important to breast cancer survivors**, but that health care providers are not properly measuring.

Needs assessment

The following section reviews needs assessments. Needs assessments represent one type of assessment tool used to identify where there is a lack of supportive care resources. Needs assessments are generally used at the population level to generate delivery service recommendations (205). Needs assessments can also be used for program evaluation (60). Needs assessments do not examine the severity of a problem, but rather if a problem is present or absent and if the health care system needs to create resources for the problem. They are not designed for clinical use. However, a review of needs assessments will be provided to examine the type of needs that breast cancer

survivors may have. **The CSPro will expand upon these needs assessments by being specific to recent breast cancer survivors problems and be designed for clinical use**.

Bonevski and colleagues developed the 54-item Supportive Care Needs Survey, which identifies the needs of cancer patients (39). The generic survey (not specific to one type of cancer) consists of five factors (Psychological, Health system and information, Physical and daily living, Patient care and support, Sexuality). Boyes and colleagues conducted additional analyses (i.e., exploratory factor analysis, confirmatory factor analysis, convergent validity, internal reliability) on the Bonevski et al. sample to construct a 34-item Supportive Care Needs Survey Short Form (45). Both studies utilized a heterogeneous group of cancer patients. While there are advantages to the use of a generic scale across cancer diagnoses (e.g., generalizability), there is evidence that type of needs, or problems, present are dependent on cancer diagnosis (102).

The Supportive Care Needs Survey-Short Form has been used in a study of cancer survivors (229). Knobf and colleagues distributed the Supportive Care Needs Survey Short Form to a heterogeneous sample of cancer survivors (N = 888) in Connecticut. The purpose of the study was to understand the needs of cancer survivors in that state. The study classified the cancer survivors as receiving cancer diagnoses less than 1 year ago, between 1 and 5 years ago, and more than 5 years ago. Because the instrument was validated in cancer patients, it did not reflect all of the needs of cancer survivors. The study did not specify which cancer survivors' needs were not included in the original Supportive Care Needs Survey. The researchers added 28 additional items to the self-report instrument, which were not specified in the study's publication. Multiple methods were used to construct these items. The Connecticut Cancer Partnership's Survivorship

Committee recommended some of the questions, whereas others were based on a literature review, community-based forums, or extracted from the Supportive Care Needs Survey-long form. Ten of the items focused on "needs of the more diverse Connecticut population" (p. 3) and 18 of the items focused on problems or barriers that cancer survivors may experience. However, these items, and the instrument itself, were not validated on cancer survivors post-primary treatment or for clinical use.

Patient Reported Outcomes Measurement Information System (PROMIS)

The following section reviews a database of patient reported outcomes. The CSPro will include some of these items. In response to the National Institutes of Health's Roadmap for Medical Research, in which the need for an improvement in clinical outcome assessment was highlighted, a collaborative group of researchers developed Patient Reported Outcomes Measurement Information System (PROMIS) (3). PROMIS includes valid, reliable, and generalizable self-report measures for use in patient populations (e.g., cancer, cardiovascular disorders, neuromuscular disorders). Researchers can receive access to the item bank to develop individualized self-report measures for clinical trials and clinical use. Researchers have the option to either use the measures in paper-and-pencil format or through a computerized adaptive testing system. The items evaluate symptoms (e.g., fatigue, pain, sexual function, sleep disturbance) that are applicable to a wide range of chronic diseases. In the clinic, PROMIS is intended to allow health providers to modify a patient's treatment based on the patient's response profile (71). Six researchers from six primary research sites (i.e., Duke University, Stanford University, State University of New York at Stony Brook, University of North Carolina, University of Pittsburgh, University of Washington) participated in the

development of the PROMIS database. The Advisory Panel on Health Outcomes included 22 health outcomes experts and clinical research experts who reviewed the process. PROMIS was conceptualized within the World Health Organization's definition of health as including a physical, mental, and social framework. The PROMIS item bank includes five domains: physical functioning, fatigue, pain, emotional distress, and social role participation (71).

The Statistical Coordinating Center analyzed 11 large datasets that included patient reported outcomes from more than 50,000 respondents (71; 308). Researchers reviewed items and selected ones that fell under PROMIS' five domains. Researches removed items that were inconsistent with the domain, were redundant, were not universally applicable, were disease specific, or were confusing (113). Item response theory reduced the redundancy of items in the item bank through examination of item correlations (154). A PROMIS library of approximately 10,000 items was constructed to allow for the identification, cataloguing, refinement, and subsequent writing of items that would represent the PROMIS item banks. The PROMIS library was subjected to quantitative statistical analyses (e.g., application of item response theory, exploratory factor analysis), as well as feedback from focus groups and cognitive interviews about the items (71). Researchers conducted 28 focus groups and 155 cognitive interviews on patient populations. Participants were recruited from general medical clinics, rehabilitation clinics, arthritis registries, and outpatient psychiatric clinics (113). The purpose of the focus groups was to evaluate domain coverage (70). Researchers asked participants whether the topics covered were the topics most relevant to them (113). Cognitive interviewing reviewed clarity of items, the steps participants use to recall the

answer, motivation and social desirability, and the overall response process with patients. PROMIS items were validated against previously validated instruments, which PROMIS researchers referred to as legacy instruments (71).

Current need

More recently, the National Cancer Institute's Office of Cancer Survivorship has announced the need for assessment of cancer survivors in the context of coordination of care for cancer survivors (R21 PA-09-130). As reviewed above, there is a lack of brief, yet comprehensive self-report measures with clinical utility. Many measures are validated in cancer patients. The generalizablity of these self-report instruments to cancer survivors who completed treatment within the past five years is of concern to researchers and health care providers because the type of problems cancer patients and survivors experience may differ (e.g., cancer survivors report of fear of recurrence post-primary treatment, worry over finances typically initiates post-treatment). Self-report instruments are often designed to measure specific constructs (e.g., fatigue or depression or cognitive limitations) across cancer diagnoses in research settings. Clinically, it is not economically viable and it is time demanding to administer multiple self-report measures that cover specific constructs. Also, a brief multidimensional and clinically valid self-report tool such as the CSPro, could be used to augment Survivorship Care Plans or another survivorship care planning method (e.g., treatment summaries). **The CSPro will assess areas that the Institute of Medicine identified as important for cancer survivors** (e.g., health service needs, symptoms, protective health behaviors, function) (216), **but are not comprehensively covered in many of the Survivorship Care Plans**.

Table 2 reviews four Survivorship Care Plans that the American Cancer Society recommends (10). As reviewed in the table, certain problem areas are not assessed. Also, the problems that are assessed only include one to two questions concerning the problem. Therefore, the assessment of the problem may be incomplete and the psychometrics unstable. For instance, the Prescription for Living Survivorship Care Plan has the provider check a box whether the survivor experiences sleep problems and advises that additional screening should be conducted. However, the Survivorship Care Plan does not include the items to conduct such screening. Other areas only include general recommendations that are not personalized to the individual breast cancer (e.g., the Lance Armstrong Foundation Survivorship Care Plan (234) provides general recommendations on diet and physical activity). The Institute of Medicine recommends that Survivorship Care Plans and follow-up care be personalized to the individual survivor (216).

INSTRUMENT DEVELOPMENT

This section provides an understanding of the historical and current practice of self-report instrument development as it relates to the development of the CSPro. Self-report scale construction of psychological constructs largely originated within the psychology field (106). In the late 19th century, Francis Galton's use of statistical models provided significant advancements in the field. Davis suggested that individual differences based on the normal curve (161) and the use of the correlation (162) refined measurement (106). Alfred Binet's contributions have also shaped scale construction and item measurement (106). Binet is credited with use of multiple items, item selection (item analysis), use of a total score, standardized administration, and scale validation.

Several decades later, Spearman introduced the notion that correlational analysis could measure latent variables, or variables that are inferred rather than directly measured (340), and the concept of reliability (341). Davis suggested that Spearman's foresight into correlational analysis and latent variables allowed for the future development of factor analysis (106). These advancements in scale construction have a direct influence on the CSPro's construction. The CSPro includes multiple items that measure latent variables. Also, items are subjected to principal component analysis and tests of reliability.

Scale construction

The following section reviews scale construction, a process of direct relevance to the CSPro. Davis discussed five stages of scale construction: scale design, item construction, item selection, scale validation, and scale evaluation (106). During scale design, the construct is defined and attention is given to practical considerations (e.g., reading level, number of items). It is during this stage that the scale's developers determine whether the scale will be based on a theoretical perspective (the construct under consideration) or a practical perspective (predicting a criterion). Item construction includes determining the measurement scale and number of response categories. Item selection can be conducted with factor analysis, an internal criterion method. External criterion methods (e.g., correlation of items with externally related variables) also assist in item construction. Scale validation (e.g., exploratory and/or confirmatory factor analysis) is an extension of this process. During scale evaluation, the self-report measure's theoretical (scale's true representation of the construct), psychometric (reliability and validity, Table 3), administrative (cost-benefit analysis), cultural

(generalizable and acceptable), and ethical (potential to cause harm) properties are evaluated.

Scale evaluation

In 1994, the Medical Outcomes Trust formed the Scientific Advisory Committee to identify and review quality of life and health status self-report measures (242). The Scientific Advisory Committee established a set of rigorous criteria to complete this review. Since that time, the committee has revised these criteria to reflect advancements in theory and statistical technology. Currently, the criteria include eight key components: conceptual and measurement model, reliability, validity, responsiveness, interpretability, respondent and administrative burden, alternate forms, and cultural and language adaptations (327). Table 4 provides a review of the criteria. While it may be unrealistic to achieve all criteria in the initial construction of the CSPro, the criteria can provide a framework to plan future studies related to the CSPro.

INTERNET RESEARCH

The current study's data are collected via the Internet. Therefore, a review of the benefits and limitations of scientific research conducted on the Internet is provided. Scientific research conducted on the Internet permits researchers to recruit participants outside the researcher's local area. There are a growing number of individuals who use computers and the Internet for personal and professional purposes (32). In 2002, 52% of Americans used search engines (299). In 2012, the percentage rose to 73% of Americans (299). Internet research allows participants to complete survey material at their convenience, thereby reducing participant burden. Also, this methodology can reduce the cost of a study (paper, mailing cost).

Gosling and colleagues noted that many researchers question the validity of data collected from the Internet without having empirical evidence to support their critique (176). Consequently, they conducted a study comparing results from an Internet sample (N = 361,703) with 510 samples (derived from 156 articles) published in the *Journal of Personality and Social Psychology* in 2002. They examined the difference in demographic characteristics, as well as measures of adjustment, depression, self-esteem, and personality. The Gosling and colleagues' study sample was representative of individuals in the United States. However, it was a convenience sample. Results indicated that non-Internet samples were on average between 71% (experimental design) and 77% (correlational design) female. The study's authors did not operationally define experimental and correlational designs. The Internet sample was more representative of the general population, with only 57% of the sample being female. The Internet sample recruited a more representative sample when considering socioeconomic status than non-Internet samples. Non-Internet samples and the Internet sample were similar on race, both being less demographically diverse than the U.S. population. Age was also similar between the two recruitment methods. The Internet sample did not significantly differ from the non-Internet sample on depression or adjustment, negating the myth that Internet samples are maladjusted. Also, findings between the two sampling methods were similar on measures of self-esteem and personality.

Recently, Smith and colleagues compared the quality of data (e.g., participant non-response, item non-response, sampling bias) among a sample of testicular cancer survivors who either completed a survey online or via the postal service (332). The survey examined psychosocial problems due to testicular cancer. The study did not state

whether the study sample was representative of testicular cancer survivors in the United States. Response rate was significantly higher for participants who completed the survey on the Internet (90%) as compared to the postal version (73%). Additionally the Internet sample returned the survey more quickly and required fewer reminders to complete the survey. There was no significant difference between numbers of missing items between the two methods. While age, relationship status, employment status, language spoken, or country of birth did not differ between samples, the Internet sample included a large percentage of "tertiary-educated" survivors and managers or professionals. Of note, the study did not operationally define tertiary-educated nor did it indicate the validity of the study sample. Considering the aforementioned advantages, **the CSPro benefits from the study material being administered via the Internet**.

STUDY RATIONALE

The prevalence of breast cancer survivors is on the rise, exceeding the healthcare system's resources to manage and treat breast cancer survivors (333). The current shortage of oncologists, primary care providers, and nurses is expected to become more severe in the future (53; 128; 346). Efficient and feasible methods to detect, treat, and manage the long-term and late effects of breast cancer are needed. Breast cancer survivors have expressed a need for individualized care planning that includes psychological, social, and physical effects of cancer, as well as a focus on nutrition and exercise (196; 222). However, current survivorship care planning methods (e.g., Survivorship Care Plans) do not comprehensively assess the psychological, social, and functional symptoms or preventive health behaviors of breast cancer survivors.

There is a need to augment what is currently available in cancer survivorship care (e.g., treatment summaries, Survivorship Care Plan) with a multidimensional measure of health service needs, symptom burden, function, and protective health behaviors. A barrier to survivorship care planning is when self-report clinical assessment tools are too long and time demanding (283; 349). Therefore the self-report measure should be brief. The CSPro's domains (i.e., health service needs, symptom burden, function, health behaviors) have an impact on cancer survivorship (124; 144; 188; 197) as depicted in the study's model (Figure 3). As illustrated in the study model, research is inconsistent concerning whether medical and demographic variables influence health service needs, symptom burden, function, and protective health behaviors (123). Consideration needs to be given to a breast cancer survivor's social desirability. Social desirability is conceptualized as a breast cancer survivor's intent to minimize problems with symptoms, function, and health service needs, as well as to exaggerate her engagement in preventative health behaviors. A breast cancer survivor's perceived health status also may have a negative or positive impact on a breast cancer survivor's self-report of health service needs, symptom burden, function, and health behaviors. Although environmental factors will not be evaluated in the CSPro, it is important to note their potential impact on cancer survivorship (Figure 4).

The current doctoral dissertation research project's purpose was to develop the CSPro and establish its psychometric properties. **The CSPro is intended for women within the first five years of completion of primary treatment for breast cancer.** The CSPro will screen for symptoms (e.g., fatigue), functional problems (e.g., cognitive function), health behaviors (e.g., cigarette smoking), and health service needs (e.g.,

healthcare competence). Healthcare providers can use the CSPro to identify the most statistically elevated problems, which is explained in more detail below, that breast cancer survivors experience. After the identification of a problem with the CSPro, the healthcare provider can either deliver an intervention in the office or refer the survivor to a more appropriate service.

Considering the Chronic Care Model (379), the CSPro can be classified as a delivery system design tool. The CSPro provides an organized method to collect patient information and review problems. It is designed to assist the provider and survivor in creating a plan, setting goals, and with repeated administration the healthcare provider and survivor can review results and adjust the plan as needed. Clinical use of the CSPro may be one approach to enhance continuity and quality of care. It may improve communication among providers. The CSPro may also be a communication tool through the facilitation of medically relevant conversations between provider and survivor. However, empirical research is needed to support these hypotheses.

The CSPro is designed for healthcare providers to administer in a clinical setting. The healthcare provider can input the breast cancer survivor's responses into a Microsoft Excel® file, which will have a programmed scoring system. The healthcare provider will print a visual profile of the breast cancer survivor's standardized scores. The visual profile will contain the constructs (e.g., cigarette smoking, exercise/physical activity, alcohol consumption, diet, and weight change) under each domain (e.g., health behaviors see Figure 9). The scores will be standardized to T-scores, which have a mean of 50 and a standard deviation of 10. Confidence intervals (95%) for each score will be provided. The CSPro's responses will then help guide the clinic visit. The health provider and

breast cancer survivor will have the opportunity to focus on the most statistically elevated problems. The CSPro is designed to bring awareness of the problems into the office visit and to facilitate discussion about the problems between the healthcare provider and breast cancer survivor. The healthcare provider and breast cancer survivor can then collaboratively decide appropriate interventions for the problems.

SPECIFIC AIMS AND HYPOTHESES

Specific Aim 1: To develop a preliminary version of the CSPro by assembling the most valid and reliable items available to measure problems within four domains: *symptom burden* (fatigue, depressive symptoms, anxiety, pain, fear of recurrence, body image, fertility distress), *function* (social relationships, work, sexual function, cognitive function, sleep disturbance), *health behaviors* (cigarette smoking, alcohol consumption, physical activity/exercise, diet, weight change), *health services* (health information, health care competence, communication, economic demands).

Hypothesis 1: It is hypothesized that the project will create a preliminary version of the CSPro by assembling valid, reliable items in the four domains.

Rationale: The items will be selected through systematic literature reviews from available self-report measures and the PROMIS database. Researchers have developed previous self-report scales in cancer survivors using similar methodology (39; 61; 72; 205; 218; 343; 358). Psychometrically sound measures of the constructs to be included in the CSPro exist in the literature. PROMIS provides valid and reliable indices of the constructs (70; 90; 309).

Specific Aim 2: To determine the factor structure of each of the four domains (health service needs, symptom burden, function, and health behaviors) with participant item responses through principal component analyses.

Hypothesis 2.1: There will be seven underlying factors for symptoms (fatigue, depressive symptoms, anxiety, pain, fear of recurrence, body image, fertility distress).

Rationale: Breast cancer survivors report these seven symptoms. Each symptom has distinct diagnostic criteria and clusters of associated problems (13; 170; 358; 364).

Hypothesis 2.2: There will be five underlying factors for function (social relationships, work, sexual function, cognitive function, sleep disturbance).

Rationale: These five functional problems consist of separate signs and symptoms that define the different functions (36; 41; 46; 245; 326).

Hypothesis 2.3: There will be five underlying factors for health behaviors (cigarette smoking, alcohol consumption, physical activity/exercise, diet, and weight change).

Rationale: These health behaviors are achieved through separate actions and activities, which define the five different health behaviors (28; 33; 119).

Hypothesis 2.4: There will be four underlying factors for health service needs (health information, health care competence, communication, and economic demands).

Rationale: These four areas define quality health care for cancer survivors (141; 216). Although they are related, they are four discrete constructs.

Specific Aim 3: To determine the validity of the principal component factor analyses, parallel analyses were conducted.

Hypothesis 3.1: The four parallel analyses will suggest that a fewer number of factors should be retained than the results of the principal component analysis.

Rationale: Interpretation of the principal component analysis based on the Kaiser criterion can lead to an overestimation of factors due to sampling error. Cattell's scree plot, also utilized in principal component analysis, introduces subjectivity into analyses. Parallel analysis accounts for sampling error, and has been consistently shown to produce results suggesting a more accurate number of factors to retain (192).

Specific Aim 4: To determine the psychometric properties of the CSPro, including construct validity, discriminant and convergent validity, internal consistency, and test-retest reliability.

Hypothesis 4.1: Correlations among sub-scales for each of the four domains will produce at least moderate associations (i.e., $r \geq 0.30$).

Rationale: Although the sub-scales, or factors, are conceptualized as discrete concepts, research indicates some correlations between the factors (24; 36; 52; 174; 260; 312; 330). Therefore, there will be moderate correlations between the sub-scales of each domain.

Hypothesis 4.2: Correlations between scale items measuring different constructs (e.g., access to health care and symptom burden, health behaviors and symptom burden) will result in low correlations (i.e., $r < 0.30$).

Rationale: As a test of discriminant validity, there will be low correlations between scales of different constructs. While these domains are related, they are comprised of different factors. Research indicates inconsistent relationships between these domains (22; 79; 144; 174; 188; 271; 300).

Hypothesis 4.3: Each scale will have at least a moderate correlation (i.e., a minimum of 0.30) with previously validated measures of the scale's constructs.

Rationale: There is no current literature to support this hypothesis.

Hypothesis 4.4: The correlation between items on the same sub-scale will result in reliability at a minimum of 0.70.

Rationale: Items on each sub-scale will be representative of the same construct, or factor, and thus be highly correlated with one another.

Hypothesis 4.5: The correlation between the initial administration of the proposed measure to the study sample and administration two weeks later to the study sample will result in test-retest reliability at a minimum of 0.70.

Rationale: There is no current literature to support this hypothesis.

Specific Aim 5: To determine which domain of the CSPro has the highest correlation with breast cancer survivors' general self-rated health at time of CSPro administration.

Hypothesis 5.1: The health behaviors sub-scale will have the highest correlation with general self-related health.

Rationale: Research indicates that perceived health is correlated with health behavior practice in breast cancer survivors (144).

Specific Aim 6: To determine if breast cancer survivors' social desirability, age, and time since completion of primary treatment are significantly correlated with health service needs, symptom burden, function, and health behaviors at time of initial CSPro administration.

Hypothesis 6.1: There will be a significant correlation between social desirability and each of the four domains (i.e., symptom burden, function, health behaviors, and health services).

Rationale: Breast cancer survivors have expressed concern that if they report to their physicians that they experience poor cancer-related well-being that their physicians will perceive the report as exaggerated (318).

Hypothesis 6.2: There will be a significant correlation between participant age and each of the four domains (i.e., symptom burden, function, health behaviors, and health services).

Rationale: Age can influence health service needs, symptom burden, function, and health behaviors in breast cancer survivors (43; 79; 85; 93; 200; 293).

Hypothesis 6.3: There will be a significant correlation between time since completion of primary treatment and each of the four domains (i.e., symptom burden, function, health behaviors, and health services).

Rationale: Breast cancer survivors late and long-term effects may increase or decrease over time since completion of primary treatment (4; 42; 112; 131).

Chapter II: Methods

The study included three phases: (1) development of CSPro, (2) administration of CSPro to breast cancer survivors, (3) data analysis and item refinement. Figure 5 illustrates the study's phases.

PARTICIPANTS

Inclusion criteria for the breast cancer survivors were self-reported female gender, diagnosed with breast cancer stages I-III, completion of primary treatment no more than five years prior to study, ages 21 and older, and Internet access. Breast cancer survivors with a history of a previous cancer or a second cancer were excluded from the study. Recruitment was limited to breast cancer survivors in the first five years post-primary treatment because (1) cancer survivors report increased symptom burden during this time (206; 229; 256; 357; 375), and (2) the CSPro is intended to be integrated into routine follow-up care (e.g., surveillance) that breast cancer survivors receive for five years post-completion of treatment (224).

RECRUITMENT

Following the Uniformed Services University of the Health Sciences Institutional Review Board Approval, participants were recruited by advertisements and flyers distributed to comprehensive cancer centers and primary care clinics across the United States, support groups, hospital bulletin boards, coffee shops, Internet advertisements, and websites. See Appendix A for Institutional Review Board approval letter and flyers. Letters were sent to each recruitment site asking them to distribute fliers to breast cancer survivors meeting study inclusion criteria. Letters were sent to the contact information

listed on relevant Internet websites requesting that they post recruitment information about the study on their website. Principal investigator and study personnel also made phone calls to recruitment contacts to establish connections for recruitment. Appendix B includes a list of recruit sources for the study.

All study participants used a web-based interface to complete study measures. Participants completed a pre-screening measure (e.g., gender, cancer status/time since completion of primary treatment; Appendix C). If a potential participant met the inclusion criteria, then she was directed to complete the rest of the study material. Informed consent (Appendix D) was electronically signed prior to completing the study's measures. Efforts were made to recruit a sample that was racially and ethnically representative of those diagnosed with breast cancer, as illustrated in Table 5. Calculations to determine targeted enrollment were conducted by considering the racial and ethnic demographics of the U.S., while adjusting for the differences in breast cancer incidence by race and ethnicity.

MEASURES

Demographic and medical

Participants completed questions regarding demographic and medical information using questions that our research group has used in three independent Internet surveys (48; 58; 188). Questions are listed in Appendix C. Demographics consisted of ethnicity, race, age, marital status, and education. Medical questions included location of tumor, stage of tumor, treatment received (i.e., surgery, radiation, chemotherapy), time since completion of primary treatment, adjuvant therapies with dates initiated and completed (if applicable), non-cancer related medications, menopausal status, and self-report of any

additional health issues. Medical information was self-reported because the collection process is in a non-clinical context. Self-report of medical information (i.e., treatment received, date of treatments, tumor characteristics) is consistent with that documented on medical charts (251).

Cancer Survivor Profile (CSPro)

The preliminary 105-item CSPro (Appendix C) was constructed based on the scientific literature in breast cancer. The preliminary CSPro assessed four domains: symptom burden (i.e., fertility distress, depressive symptoms, anxiety, pain, body image, fear of recurrence, fatigue), function (i.e., cognitive function, work, sexual function, sleep, social relationships), health behaviors (i.e., diet, exercise/physical activity, cigarette smoking, alcohol consumption), and health services (i.e., patient-provider communication, health information, healthcare competence, economic demands). Appendix E includes the names and version numbers of the instruments that PROMIS items are from, and the original sources of the non-PROMIS items. Additional information about PROMIS instruments can be found at www.NIHPROMIS.org.

Gold Standard Measures

Center for Epidemiologic Studies Depression Scale

The Center for Epidemiological Studies Depression Scale (CES-D) is a 20-item measure of depression (Appendix C) (304). It focuses on affective depression rather than the somatic experience of depression, which can confound measurement in medical populations. The CES-D has been used in cancer populations and a review indicates it has strong psychometric properties (376). It has shown to be internally consistent ($\propto$ = 0.75-0.90), with good specificity (0.79-0.85), positive predictive validity (0.53-0.92), and

negative predictive validity (0.94-1.0). The CES-D was included in the present study to determine convergent validity with CSPro depressive symptoms and discriminant validity with CSPro diet. This measure is in the public domain.

Behavioral Risk Factor Surveillance Questionnaire (BRFSS) selected items

Selected items from the 2011 Behavioral Risk Factor Surveillance Questionnaire (BRFSS) (74) (Appendix C) were used to determine convergent and discriminant validity of the CSPro. The items from the 2011 BRFSS examine physical activity/exercise. A review of the psychometric properties of the BRFSS indicated that it demonstrates acceptable validity and reliability (280). The BRFSS physical activity/exercise questions are standardized into metabolic equivalent of task (MET) and calculations for meeting the Centers for Disease Control guidelines for moderate (150 minutes/week) and vigorous (75 minutes/week) physical activity are conducted (73). The BRFSS is in the public domain).

Modified-Patient Perceived Involvement in Care Scale

The Modified-Patient Perceived Involvement in Care Scale (M-PICS) is a 20-item self-report measure that evaluates patient-provider communication (Appendix C) (335). The M-PICS has an internal consistency of 0.87 and its convergent validity ranges between 0.80 and 0.90. The M-PICS was used to establish convergent validity with the CSPro's patient-provider communication and discriminant validity with the CSPro's cognitive function. Permission was provided to use the M-PICS in the present study.

Pittsburgh Sleep Quality Index

The Pittsburgh Sleep Quality Index (PSQI) is a self-report questionnaire that measures sleep quality for research and clinical practice (Appendix C) (57). The PSQI has been validated in cancer patients and survivors with strong psychometric properties (27; 57). The PSQI has demonstrated internal consistency ($\propto$=0.72)(212) and construct validity ($r > 0.69$) (66) in cancer survivors. In the current study, the PSQI was used to establish convergent validity with the CSPro's sleep sub-scale and divergent validity with the CSPro's health information sub-scale. The PSQI is available for research use.

Outcome Measure

Self-perceived general health

Participants responded to a General Self-Rated Health Question. The question is, "In general, how would you rate your health?" (110). Participants selected among the following response options: "excellent, very good, good, fair, poor." This single item of perceived health is predictive of all-cause mortality. A meta-analysis of prospective community-based cohort studies revealed that the all-cause mortality relative risk was 1.23 (95% confidence interval 1.09, 1.39) for "good," 1.44 (95% confidence interval 1.21, 1.71) for "fair," and 1.92 (95% confidence interval 1.64, 2.25) for "poor" when compared to participants who endorsed "excellent" health status (110). Follow-up ranged from 15 months to 21 years. Perceived general health is often conceptualized as a unidimensional construct, supporting the use of a single-item question (44). The single item question also reduces participant burden.

Measure to examine confounder

Social Desirability Scale Short Form

Social desirability has a greater effect on in-person laboratory studies than on Internet based studies (220). However, when the CSPro is used clinically it may be completed during an office visit where social desirability may be more influential. Therefore, it is important to consider this factor in participant responses. Participants completed the Social Desirability Scale Short Form (Appendix C) (347). Strahan and Gerbasi reduced Marlowe and Crowne's (103) 33-item measure to a 10-item scale. The M-C 1 (10) was found to be reliable and correlated highly with the full scale (0.80 or above). Fischer and Fick conducted confirmatory factor analyses on six separate short form versions of Marlowe and Crowne's Social Desirability Scale (145). The study results indicated that Strahan and Gerbasi's M-C 1 (10) was the most valid and reliable short-form. It had high internal consistency ($r = 0.97$) and correlated highly with the full-item scale ($r = 0.96$). This measure is in the public domain.

PROCEDURE

Phase 1

Specific Aim 1: To develop a preliminary version of the CSPro by assembling the most valid and reliable items (as per criteria described below) used to measure problems within four domains: *symptom burden* (fatigue, depressive symptoms, anxiety, pain, fear of recurrence, body image, fertility distress), *function* (social relationships, work, sexual function, cognitive function, sleep disturbance), *health behaviors* (cigarette smoking, alcohol consumption, physical activity/exercise, diet, weight change), *health*

services (health information, health care competence, communication, economic demands).

Systematic search procedure of items to include from PROMIS

Reviewers (see Method section below) systematically selected Likert items from the PROMIS item bank to develop the preliminary version of the CSPro. As illustrated in Table 6, PROMIS includes valid and reliable patient-report items that measure fatigue, pain, depression, anxiety, cognitive function, sleep disturbance, sexual function, social relationships, and alcohol consumption. These item banks include more items than is feasible to include in the preliminary version of the CSPro. To determine which items to include, systematic searches of the qualitative scientific literature on breast cancer survivors were conducted. PROMIS items that reflected the breast cancer survivors' descriptions of the problems were selected. Detailed selection criteria are presented below. The PROMIS item bank does not include all constructs that the CSPro was intented to measure (Table 6). Therefore, for items not available in PROMIS, items were systematically selected from previously validated measures identified through a systematic review of the scientific literature.

Method

There were three reviewers involved in all of the systematic searches for the study. Reviewers One (principal investigator of present study) and Two were doctoral candidates in Medical and Clinical Psychology at the Uniformed Services University of the Health Sciences (USUHS). Reviewer Three was a professor in Medical and Clinical Psychology at USUHS, and the principal investigator's major and research advisor. Reviewer One met with a USUHS research librarian to determine the proper search

terms, search limits, and search engines (described below) for the systematic searches. Reviewer One conducted all systematic searches. Reviewer One and Two independently reviewed all titles and abstracts of the saved searches to determine whether articles met inclusion for full text review. Following the reviews, Reviewer One compared the results and for any discrepancies Reviewer Three determined if studies met inclusion criteria.

Reviewer One located all articles that met criteria for full article review (i.e., identified during the abstract and title review). This reviewer entered the studies' themes for each construct into tables (see Appendix 7 Tables G1-G7). Reviewer One identified themes based on articles' use of thematic analysis and through reading study findings (e.g., if fatigue was described as problem area). Reviewers One and Three reviewed the tables for content analysis and agreement on classification of themes. Together, Reviewers One and Three selected PROMIS items consistent with the most frequent themes identified. Figure 6 provides an overview of the methodology used to select items from PROMIS. If the PROMIS item bank did not contain items consistent with the most frequent themes identified in qualitative searches, then Reviewer One and Three collaboratively constructed items. The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition Text Revision (DSM-IV-TR) (13) diagnostic criteria was used to generate items when the systematic searches did not produce articles for a construct.

The CSPro retained the anchors used in the PROMIS items. Items concerning intensity have the following response options: 1 = Not at all, 2 = A little bit, 3 = Somewhat, 4 = Quite a bit, 5 = Very much. Items concerning frequency have the following response options: 1 = Never, 2 = Rarely, 3 = Sometimes, 4 = Often, 5 = Always.

Search terms

The systematic searches of the qualitative scientific literature identified breast cancer survivors' experience with fatigue, pain, depressive symptoms, anxiety, cognitive function, sleep disturbance, sexual function, and social relationships. The databases PubMed (National Library of Medicine), EMBASE (Elsevier), PsycINFO (Ovid), Web of Science (Web of Science), and CINAHL (EBSCO, CINAHL) were utilized. Limits of the search (inclusion criteria) included qualitative studies, English language, humans, non-metastatic breast cancer (Stages I-III), and adults (18 + years).

Symptom burden. The search terms for *fatigue* included (breast neoplasms) AND (fatigue OR mental fatigue OR physical fatigue OR chronic fatigue syndrome) AND (qualitative research OR focus groups). The search terms for *pain* included (breast neoplasms) AND (pain OR chronic pain) AND (qualitative research OR focus groups). The search terms for *depressive symptoms* included (breast neoplasms) AND (depression or depressive disorder OR depressive disorder, major OR adjustment disorder) AND (qualitative research OR focus groups). The search terms for *anxiety* included (breast neoplasms) AND (anxiety OR anxiety disorders) AND (qualitative research OR focus groups).

Function. The search terms for *cognitive function* included (breast neoplasms) AND (executive function OR attention OR memory OR cognition) AND (qualitative research OR focus groups). The search terms for *sexual function* included (breast neoplasms) AND (sexual dysfunction, physiological OR sexual dysfunction, psychological) AND (qualitative research OR focus groups). The search terms for *social relationships* included (breast neoplasms) AND (interpersonal relations OR social support) AND (qualitative research OR focus groups). The search terms for *sleep*

included (breast neoplasms) AND (sleep OR sleep disorders) AND (qualitative research OR focus groups).

Health behaviors. The search terms for *alcohol consumption* included (breast neoplasms) AND (alcoholism OR alcohol-related disorders OR alcohol drinking) AND (qualitative research OR focus groups).

Systematic search procedure of items not included in PROMIS

Systematic searches of the scientific literature identified measures and specific items of problem areas not included in the PROMIS item bank (i.e., health information needs, healthcare competence, provider-patient communication, economic demands, fear of recurrence, body image concerns, fertility distress, work function, exercise, diet, smoking, and weight change). Figure 7 provides an overview of the methodology used to select non-PROMIS items. As described for items included in PROMIS, Reviewer One met with a research librarian to determine the proper search terms, search limits, and search engines (described below) for the systematic reviews. Reviewer One conducted the searches. Reviewer One and Two independently reviewed all titles and abstracts of the saved searches. Following the reviews, Reviewer One compared the results. Reviewer Three resolved any discrepancies.

Method

Reviewer One analyzed full-text articles that met inclusion to identify the self-report scales that measure the specified constructs. Efforts were taken to locate all other validation studies of self-report scales. Measurement properties of the scales were recorded in tables. Reviewers One and Three examined measures' measurement properties, including reliability (i.e., internal consistency and test retest), validity (i.e.,

construct, convergent, divergent), and factor loadings. Self-report measures with the strongest validity and reliability were selected. Items with a factor loading of |0.65| and above were included on the preliminary CSPro, with a maximum of six items for each construct. When a measure did not utilize factor analysis, and no other measure in that construct did, beta weights or the most relevant items based on the scientific literature were utilized to select items. Reviewer One contacted the corresponding author of the measure to request permission to use items in the CSPro, if the measure was not in the public domain.

Examination of previous scales is an integral step to develop an assessment tool to optimize the relevance, importance, and discriminatory ability of the items (348). Identification of the wording and rating scales of previous scales, which was offered by Reviewers One and Three, ensures a more psychometrically sound assessment tool (348). To reduce participant confusion, the same anchors used in the PROMIS items were used for the non-PROMIS items, when applicable to the items. Items concerning intensity had the following response options: 1 = Not at all, 2 = A little bit, 3 = Somewhat, 4 = Quite a bit, 5 = Very much. Items concerning frequency will have the following response options: 1 = Never, 2 = Rarely, 3 = Sometimes, 4 = Often, 5 = Always.

Search terms

A systematic literature search was conducted using the databases PubMed (National Library of Medicine) and Health and Psychosocial Instruments (HaPI) (OVID). HaPI is designed to identify instruments in research articles based on search parameters. Limits of the search included English language, humans, non-metastatic breast cancer

(Stages I-III), and adults (18 + years). An additional inclusion criterion consisted of quantitative study design (i.e., cross-sectional or longitudinal).

Symptom burden. Search terms for *fear of recurrence* included (125) AND (fear OR neoplasm recurrence OR attitude to death OR anxiety OR health status) AND (health surveys OR questionnaires). Search terms for *body image concerns* included (125) AND (body image) AND (health surveys OR questionnaires). Search terms for *fertility distress* included (125) AND (fertility OR infertility, female OR pregnancy OR women's health) AND (health surveys OR questionnaires).

Function. Search terms for *work function* included (125) AND (workplace OR job satisfaction OR employment OR employment, supported) AND (health surveys OR questionnaires).

Health behaviors. Search terms for *physical activity/exercise* included (125) AND (exercise) AND (health surveys OR questionnaires). Search terms for *weight* included (125) AND (weight loss OR weight gain OR body mass index OR body weight) AND (health surveys OR questionnaires). Search terms for *diet* included (125) AND (diet OR diet surveys) AND (health surveys OR questionnaires).

Health services. The search terms for *patient-provider communication* included (125) AND (communication barriers OR doctor patient relations) AND (health surveys OR questionnaires). The search terms for *health information* included (125) AND (consumer health information OR health knowledge, attitudes, practice OR health literacy) and (health surveys OR questionnaires). The search terms for *healthcare competence* included (125) OR (health services accessibility OR health literacy) AND (health surveys OR questionnaires). The search terms for *economic demands* included

(125) AND (socioeconomic factors OR health care costs OR insurance coverage OR health expenditures OR economics, medical) AND (health surveys or questionnaires).

Phase 2

Study measures were distributed to breast cancer survivors in an Internet format via Survey Monkey™ (350).

Sample size

Suggested sample sizes for factor analysis range from 3:1 (69) to 10:1 (130) when considering *N:p (N* [necessary sample size] to *p* [number of variables analyzed]). A minimum sample size of 100 to 200 is recommended to ensure that a correlation coefficient can adequately estimate the population (175; 185). The present sample size (i.e., n = 259) per principal component analysis meets the recommendation of a minimum of 200 participants and produces a *N:p* within the recommended range. Additionally, Monte Carlo procedures indicate that when communalities are high a smaller sample size is acceptable for principal component analysis (183). For instance, when communalities are 0.8 then a sample size of 50 produces a stable factor structure. When communalities are 0.6 then a sample size of 150 is acceptable. Communalities for the present study ranged between 0.43-0.89.

The principal investigator's doctoral dissertation committee approved a sample size of 200. The present study obtained a larger sample to be more adequately powered for tests of validity and reliability, as detailed in power analyses for each specific aim.

DATA ANALYTIC PLAN

Phase 3

Specific Aim 2: To determine the factor structure of each of the four domains (i.e., symptom burden, function, health behaviors, and health services) through principal component analyses (94; 149).

Phase 3 determined the minimal number of Likert items needed to account for the majority of variance related to the factors that comprise the CSPro. A principal component analysis was conducted on each main domain (i.e., symptom burden, function, health behaviors, health services) to identify the underlying factors within each domain and to establish factor validity (15). Principal component analysis is based on the assumption that a set of items proposed to measure a domain of interest can be condensed into the smallest number of items or subscales to explain a percent of the variance in the full set of items of a measure (348). Each item should load onto, or correlate, with the subscale with which it belongs. It should not be highly correlated with other subscales. If some items correlate across factors, then these items are removed from development of the specific scale of interest to generate a more homogeneous measure. Principal component analysis, often incorrectly referred to as exploratory factor analysis, is a data reduction technique. Unlike exploratory factor analysis it is not concerned with latent variables (94). Factors that explain the observed variables' variances are derived (149).

Principal component analysis is appropriate for survey development to assess construct validity (149). Oblique rotation (direct oblimin) was used to allow correlation among the factors. Direct oblimin is a standard method of oblique rotation. Within each domain of the CSPro the constructs are correlated (e.g., fatigue and depression within the symptom burden domain). The use of orthogonal rotation, which assumes that the factors are uncorrelated, can result in the loss of information if the factors are in fact correlated

(94). However, the use of oblique rotation would not impact the results if some of the factors were uncorrelated. Oblique and orthogonal rotations produce similar results if factors are uncorrelated. When using oblique rotation the factor pattern matrix and factor structure matrix are utilized for interpretation of results. The factor structure matrix assists with factor identification and interpretation, whereas the factor pattern matrix provides the information for factor scores and the correlation matrix (149). In the present study, both matrixes were reviewed and the final matrix (pattern matrix) was reported. In the oncology literature, when oblique rotation is used during development of self-report measures it is standard practice to only report the pattern matrix (101; 205). Items with factor loadings of |0.65| were retained. Convention is to use a criterion of |0.40| (175), but past measurement development in the breast cancer population has also used a higher factor loading criterion to reduce items on a scale (101; 345).

The relationship among breast cancer survivors' health service needs, symptom burden, function, and health behaviors is inconsistent (22; 79; 144; 174; 188). Therefore, no strong rationale is evident to analyze the four domains together and compose one main scale. Rather, four separate scales may increase the instrument's clinical utility if a survivor and her provider desire to focus on one area. It is also advised to simplify models in confirmatory factor analysis, a future step for testing of the CSPro, and limit the number of variables (149). When too many items are subject to confirmatory factor analysis it increases the chance of correlated error in the analyses.

Incomplete data

Some of the proposed constructs (i.e., cigarette smoking, alcohol consumption, fertility distress) were not applicable to all participants. When a construct is not

applicable to a participant, it will affect the principal component analyses. Data imputation will result in biased data. Using dichotomous items (e.g., smoker = Yes or No) in factor analysis would limit potentially relevant items related to a construct to be included in a measure. When constructing a measure, it is also recommended to subject multiple items for each construct into principal component analysis to ensure reliability and that the construct is well-defined (155; 184). Therefore, for items/potential factors that are not applicable to all participants separate analyses were conducted for these items. These analyses included the participants of whom the item/potential factor was applicable. The Impact of Cancer version 2 includes sub-scales to which only select participants respond (e.g., Employment Concerns, Relationship Concerns [Not Partnered], Relationship Concerns [Partnered]) (400). These sub-scales were not subjected to principal component analysis like the rest of the scale was, but were constructed based on content review and internal consistency reliability. Content review and internal consistency reliability of the CSPro items were conducted for the construction of sub-scales that were not relevant to all participants or appropriate for principal component analysis (i.e., fertility distress, cigarette smoking, alcohol consumption). Cigarette smoking questions were dichotomous and measured different aspects of cigarette smoking. These items were not appropriate for internal consistency reliability. To determine which cigarette smoking items to include in the final version of the CSPro, they were subjected to content analysis. The scientific literature was also reviewed for the items' validity and to determine how the original item source calculated scores for the items (74).

Missing data

Participates with less than 5% of data missing were included in final analysis, and mean imputation was conducted (352). Mean imputation was not conducted for cigarette smoking due to the dichotomous nature of this variable. The mean is not a meaningful measure of central tendency for categorical variables. Values were left missing for cigarette smoking, which had minimal effect on data analysis because these items were only subjected to content analysis. Casewise deletion was conducted for perceived general health due to the low number of missing cases (n =3). Removing these cases likely caused minimal effect on sample size for these analyses.

Specific Aim 3: To determine the validity of the principal component analyses, parallel analyses will be conducted.

Parallel analysis is a factor retention method that is used in conjunction with the Kaiser criterion and Cattell's scree plot to determine how many factors to retain (209). The Kaiser criterion can overestimate the number of factors. This method's theory is based on a population correlation matrix; however, within a finite sample sampling error may result. Parallel analysis corrects for the Kaiser criterion's overestimation by correcting for sampling error (192). It also has less subjectivity than the interpretation of Cattell's scree plot.

Parallel analysis is based on the assumption that actual data with a true underlying factor structure will produce eigenvalues of a greater value than those associated with simulated datasets of the same number of variables and of an equivalent sample size. To test this assumption for any given data, a number of correlation matrices of random data are generated utilizing the same number of variables and sample size. The eigenvalues from the real data are compared to the average ones of the simulated data. Factors

associated with eigenvalues from the real data that are larger than the simulated data are retained. Actual eigenvalues less than or equal to the average eigenvalues of the simulated data are attributed to sampling error. These actual eigenvalues account for less variance in true data than eigenvalues from random data. Parallel analysis suggests that actual eigenvalues (i.e., those from the real dataset) greater than the 95th percentile eigenvalues from the simulated samples should be retained.

In the present study, 1,000 datasets were simulated with a sample size of 259 for each domain. Each dataset contained an equivalent number of variables in each domain's principal component analysis. The data were generated as independent, normally distributed random variates. Principal component analyses identical to the analyses of the real data were conducted for each of the 1,000 simulated datasets. A factor was retained if the real data's eigenvalue exceeded the 95th percentile of the simulated dataset's eigenvalue. Consideration was given to the limitations of parallel analysis when retaining factors.

Specific Aim 4: To determine the psychometric properties of the CSPro, including construct validity, divergent and convergent validity, internal consistency, and test-retest reliability.

Using the reduced measure derived through the principal component analysis and parallel analysis, the overall validity and reliability of the CSPro was determined (i.e., construct validity, divergent validity, convergent validity, internal consistency, and test-retest reliability). Construct validity was determined through examining the strength of correlations among subscales that belong in each domain. The multitrait-multiitem matrix was used to determine divergent and convergent validity (59). As illustrated in

Table 3, convergent and divergent validities are types of construct validity that can be determined through multitrait-multiitem matrix. Participants' responses on previously validated self-report measures of the same constructs and different constructs were contrasted with their responses to the CSPro. The *p*-values and magnitude of correlations of all of the convergent and divergent analyses were evaluated. The above noted sample size was adequate to achieve power for construct, divergent, and convergent validity. With a sample size of 259 and when ρ is 0.18, the study has power of 0.83 to detect the correlation. Rho (ρ) is the hypothesized population correlation and *r* is the correlation observed in the sample. As seen in Table 2, $0.30 < |r| > 0.45$ represents a moderate correlation.

To determine the test-retest reliability, all the participants who met study criteria were asked to complete CSPro 2 weeks after their initial participation in the study. Pearson's correlation coefficient, *r*, were used to determine test-retest reliability. The aforementioned sample size for validity is also applicable for test-retest reliability. Cronbach's coefficient $\propto$ was calculated among each subscale's items to determine internal consistency reliability. Cronbach's coefficient $\propto$ does not provide a p-value. Therefore, a power analysis to determine sample size is not necessary, nor would it be meaningful. Research suggests a sample size of 300 – 400 for coefficient alpha (77; 228; 287). The current study is below this recommended N, but similar to other studies in the breast cancer survivor study that examined internal consistency (29; 400).

Specific Aim 5: To determine which domain of the CSPro has the highest correlation with breast cancer survivors' general self-rated health at time of initial CSPro administration.

A multiple regression between the total score of each CSPro domain (independent variables) and the single perceived general self-rated health question (dependent variable) was conducted. This analysis was conducted to determine which CSPro domain has the strongest association with general self-rated health. Examination of the partial correlations between each independent variable (CSPro domain total scores) and the dependent variable (general self-rated health) indicated the relationship between each independent variable and the dependent variable while controlling for the other independent variables. A multiple regression with four predictors requires a sample size of 84 to have 0.80 to power to detect an effect size (f^2) of 0.15 at $p = 0.01$. Therefore, the study is adequately powered for this analysis. Domain total scores were calculated by summing sub-scale item totals. The mean of each domain's total score was used because the domains were computed from a different number of sub-scales.

Specific Aim 6: To determine if breast cancer survivors' social desirability, age, and time since completion of primary treatment are significantly correlated with health service needs, symptom burden, function, and health behaviors at time of initial CSPro administration.

Pearson correlations were conducted between: (1) social desirability, (2) age, and (3) time since completion of primary treatment with total domain scores of (1) symptom burden, (2) function, (3) health behaviors, and (4) health services. A sample size of 186 has 0.82 power to detect a correlation of $\rho = 0.21$. This sample size reflects the lowest N that was included in these analyses based on available data for social desirability, age, and time since completion of primary treatment. If any of the correlations included were significant, then the scores were corrected by regressing the factor scores on the

appropriate variable (e.g., social desirability, age, time since completion of treatment). The residuals were used as the adjusted scores. Paulhus recommends this approach as one way to control for social desirability in self-report measures (291). Correlations among social desirability, age, and time since completion of treatment will not affect the aforementioned analyses because they are conceptually different constructs.

A summation of all items within a given problem area/construct (e.g., fatigue, pain) was calculated adjusting for social desirability, age, and time since completion of treatment, when needed. Scores were converted to Z-scores then T-scores for each participant.

The study included multiple tests of significance. All tests will be interpreted as significant at $p \leq 0.05$. However, caution will be advised when interpreting these results due to the potential for Type I error.

Chapter III: Results

PHASE 1

Specific Aim 1. To develop a preliminary version of the CSPro by assembling the most valid and reliable items available to measure common problems of cancer survivors that fall into four broad domains: *symptoms* (fatigue, depressive symptoms, anxiety, pain, fear of recurrence, body image, fertility distress), *function* (social relationships, work, sexual function, cognitive function, sleep disturbance), *health behaviors* (cigarette smoking, alcohol consumption, physical activity/exercise, diet, weight change), *health services* (health information, healthcare competence, communication, economic demands).

Systematic search of items to include from PROMIS

Appendix F includes Figures F1-F9 that illustrate the search results by review stage for each construct, including the number of articles extracted from each search engine and the number of papers that were included and excluded at each stage of review. The inter-rater agreement for article inclusion/exclusion ranged from 82.35%-100% (M = 91.26%). All inter-agreement reliability values are reported in Table 7.

One hundred and fifty-five articles met criteria for full text review (anxiety 19/149, cognitive function 14/117, fatigue 22/129, pain 12/102, depressive symptoms 14/165, sleep 8/137, sexual function 15/183, social relationships 51/550, and alcohol consumption 0/56). Appendix G contains tables (Tables G1-G7) illustrating the most frequent themes identified for each construct during full text review.

Systematic search of non-PROMIS items

Appendix H (Figures H1-H11) illustrates the flow chart for each construct (i.e., body image, patient-provider communication, diet, economic demands, exercise, fear of recurrence, fertility distress, health information, healthcare access, smoking, work), including the number of articles extracted from each search engine and the number of articles included and excluded at each stage of the review. The inter-rater agreement for whether an article was included/excluded ranged from 71.65%- 99.51% (M = 89.49%). All inter-rater agreement values are reported in Table 8.

Appendix I provides an overview of the measurement properties of each self-report measure that met criteria for full review. The number of self-report measures by construct were: body image (two measures), patient-provider communication (three measures), diet (one measure), economic demands to care (two measures), diet (two measures), fear of recurrence (four measures), fertility distress (three measures), health information (two measures), healthcare competence (one measure), smoking (two measures), and work (two measures). These 24 measures and their items were examined for consideration in the CSPro.

PHASE 3

Missing data and final sample

Four hundred and ninety-six participants responded to the study. One hundred and ninety-two participants did not meet study inclusion criteria, and 13 participants did not complete the study screener to determine their eligibility for the study. Three hundred and four breast cancer survivors were eligible for the study. Participants with >20% missing data or who only responded to the screener were not included in final

analyses (n = 28). Participants with less than 5% of data missing were included in final analysis, and mean imputation was conducted. Following exclusion rules, participants were removed from analyses due to self-report of previous cancer (n =4), cancer recurrence (n =2), or completing active cancer treatment > 5 years prior to initiation of study (n=11). Final analysis included 259 breast cancer survivors. There were no significant differences between the full sample and final sample on demographics (e.g., age, race, ethnicity) and medical (e.g., stage of tumor, treatment received) variables.

Participant characteristics

Breast cancer survivors (n = 259) were on average 49 years old (SD = 11.1), primarily Caucasian (n = 224, 86.8%), of non-Hispanic ethnicity (n = 239, 92.6%), and married (n =163, 63.2%). As seen in Table 5, the study sample had a higher proportion of Caucasian (study = 86.8%, national prevalence = 82%) and lower proportion of non-Hispanic ethnicity (study = 6.6%, national prevalence = 12%) breast cancer survivors than the national prevalence of breast cancer survivors. The study also included a lower proportion of Black/African American (study = 6.6%, national prevalence = 13%) and Asian (study = 1.9%, national prevalence = 4%) breast cancer survivors. The sample was highly educated with over 60% having earned a bachelor's degree or higher. The household income ranged across participants, with about 24% (n=58) of breast cancer survivors reporting a yearly income between 0 and 39,000 dollars and about 27% (n = 70) of breast cancer survivors reporting an income of 100,000 dollars or more. The majority of participants (n =139, 53.9%) were employed full-time and 30% (n=75) of participants were unemployed. About 8% of the participants who indicated unemployment were out of the workforce against choice. Demographics are indicated in Table 9.

Medical history

Participants were on average 1.99 years post-primary treatment (SD = 1.43, Mdn = 1.83). Stage II was the most common breast cancer diagnosis among participants (n = 108, 41.9%), followed by Stage I (n =99, 38.4%) and Stage III (n = 49, 19%). The majority of participants were treated with surgery (n =256, 99.2%), chemotherapy (n =192, 74.4%), and radiation (n =179, 69.4%). A majority of participants (n =152, 59.4%) also received adjuvant treatment. Table 10 provides an overview of participant medical history.

Specific Aim 2. To determine the factor structure of each of the four domains (symptom burden, function, health behaviors, and health service needs) with participant item responses through principal component analyses.

Symptom burden. A principal component analysis using oblique-rotation indicated a six-factor solution, with five items corresponding to "anxiety," five items to "pain," six items to "fear of recurrence," three items to "body image," five items to "fatigue," and four items to "depressive symptoms." Items with a factor loading of |0.65| and above were retained (Table 11). The six-factor solution accounted for 73.90% of the variance ("anxiety" 40.13%, "pain" 11.25%, "fear of recurrence" 7.86%, "body image" 5.83%, "fatigue" 5.45%, "depressive symptoms" 3.39%). The scree supported a five-factor solution. Given the inconsistency between the eigenvalues and scree plot, six factors were preliminary retained, with final decision pending further analyses in the study.

Items related to fertility distress were not included in the principal component analysis because only 17 participants endorsed the screener items indicative of fertility distress (i.e., relating to desire to have child before and/or after completion of active treatment). Internal consistency reliability was not computed due to lack of participants

needed to sufficiently compute Cronbach's alpha. This construct will not be included in the CSPro.

Function. A principal component analysis using oblique-rotation indicated a five-factor solution, with six items corresponding to "cognitive function," four items to "social relationships," four items to "sleep," two items to "sexual function," and two items to "work." Items with a factor loading of |0.65| and above were retained. The five-factor solution accounted for 71.47% of the variance ("cognitive function" 34.71%, "social relationships" 13.26%; "sleep" 10.71%; "sexual function" 7.59%, "work function" 5.21%). Results are illustrated in Table 12. Scree plot was consistent with a five-factor solution.

Health behaviors. A principal component analysis using oblique-rotation indicated a three-factor solution accounting for 57.81% of the variance. Review of factors retained "Diet" (27.91%, 3 items) and "Exercise" (18.29%, 2 items). A third, unnamed, factor with only one item loading above |0.65| was also extracted. The scree plot also suggested a three-factor solution. Final interpretation of whether factor 3 is a meaningful factor will be considered along with the results of the parallel analysis (Specific Aim 3). The Factor Pattern Matrix used in interpretation of factor scores is illustrated in Table 13.

One hundred and eighteen participants indicated they consume alcohol. Internal consistency reliability of alcohol consumption's three items was $\propto = 0.56$. The removal of one item ("I had trouble getting things done after I drank") resulted in an increase in reliability ($\propto = 0.69$), justifying inclusion of two items and the alcohol screener in the CSPro.

Health services. A principal component analysis using oblique-rotation indicated a four-factor solution, with six items corresponding to "patient-provider communication," six items to "health information," six items to "healthcare competence," and four items to "economic demands." Items with a factor loading of |0.65| and above were retained. The four-factor solution accounted for 71.78% of the variance ("patient-provider communication" 31.78%, "health information" 17.73%, "healthcare competence 12.8%, "economic demands" 9.48%). The results are illustrated in Table 14. The scree plot was also consistent with a four-factor solution.

Specific Aim 3. To determine the validity of the four principal component analyses, parallel analyses were conducted.

A parallel analysis was conducted on 1000 random samples with a sample size equivalent to that of the study (n =259) for each of the four domains. Results indicated that a five-factor solution be retained for symptom burden, a four-factor solution for function, a two-factor solution for health behaviors, and a four-factor solution for health services. Results are illustrated in Table 15. These findings suggest that "depressive symptoms" of the symptom burden domain, "work" of the function domain, and the unnamed factor of the health behaviors domain were due to sampling error and should not be retained.

Analysis of the discrepancies between the principal component analyses and parallel analyses. An exploratory analysis was conducted to further investigate whether the factor, "depressive symptoms" should be retained in the symptom burden domain. This analysis was executed due to the clinical importance of depressive symptoms and questionable reliability of parallel analysis when the first factor contains the most

variance (i.e., 40.13% variance). A principal component analysis with oblique-rotation in which a five-factor solution was fixed was conducted. Results of the fixed factor solution are presented in Table 16. Items related to "depressive symptoms" loaded onto Factor 1, "anxiety." Given the questionable clinical utility of a sub-scale containing symptoms of anxiety and depression, this combined factor will not be utilized for the CSPro. The six-factor solution containing "depressive symptoms" will be retained for further analyses.

An analysis was also conducted for the function domain. An oblique-rotation principal component analysis with a four-fixed factor solution was conducted. Items corresponding to "work" loaded with "cognitive function" (Table 17). Given the questionable clinical utility of a sub-scale including items of both work and cognitive function (e.g., not all breast cancers are employed, not all problems with cognitive function occur at work) there is justification to retain the five-factor solution.

Specific Aim 4: To determine the psychometric properties of the CSPro, including construct validity, divergent and convergent validity, internal consistency, and test-retest reliability.

Hypothesis 4.1. To determine construct validity, correlations among sub-scales of each domain were examined. Univariate correlations among sub-scales belonging to the same domain were as follows: symptom burden ranged between 0.20 to 0.70, function between 0.16 to 0.46, health behaviors between -0.13 to 0.17, and health services between 0.20 to 0.37. Detailed findings are illustrated in Tables 18-21. The hypothesis of moderate correlations (i.e., $r \geq 0.30$) was partially supported (i.e., 48% correlations $\geq$ 0.30).

Hypotheses 4.2 and 4.3. Multi-item-multi-trait testing was conducted to evaluate divergent validity among gold-standard measures (Center for Epidemiologic Studies Depression Scale [CES-D], Pittsburgh Sleep Quality Index [PSIQ], Behavioral Risk Factor Surveillance System exercise [BRFSS], Modified Version of the Patients' Perceived Involvement in Care Scale [M-PICS]) and CSPro-subscales (diet, health information, fear of recurrence, cognitive function). Analyses indicated that all correlations were below 0.30 (Table 22), supporting the hypothesis of divergent validity for the aforementioned CSPro sub-scales.

Multi-trait-multi-item testing was conducted to evaluate convergent validity among gold-standard measures (CES-D, PSIQ, BRFSS exercise, M-PICS) and CSPro-subscales (depressive symptoms, sleep, exercise, patient-provider communication). Examination of correlations among variables listed above revealed that all correlations were above 0.70 indicating convergent validity for the CSPro depressive symptoms sub-scale. The CSPro sleep sub-scale and the PSIQ ranged between 0.67-0.70. The health service's domain's sub-scale patient-provider communication ranged between 0.35-|0.53|, providing support for hypothesis 4.3. There was negligible convergent validity for the health behavior's domain sub-scale, exercise (Table 23).

Hypothesis 4.4. Internal consistency of the symptom burden domain were: anxiety $\propto = 0.88$, body image $\propto = 0.85$, depressive symptoms $\propto = 0.92$, fatigue $\propto = 0.94$, fear of recurrence $\propto = 0.91$, and pain $\propto = 0.92$. Internal consistency of the health behavior domain were: diet $\propto = 0.72$, exercise $\propto = 0.57$, and alcohol consumption $\propto = 0.64$. Internal consistency of the function domain were: cognitive function $\propto = 0.95$, social relationships $\propto = 0.91$, sleep $\propto = 0.93$, sexual function $\propto = 0.88$, and work $\propto = 0.91$.

Internal consistency of the health services domain were: patient-provider communication $\propto = 0.92$, health information $\propto = 0.93$, healthcare competence $\propto = 0.90$, and economic demand $\propto = 0.86$. Hypothesis 4.4 was primarily supported. The internal consistencies were above 0.70 for the Symptom Burden, Function, and Health Services domains. They were only partially above 0.70 for the Health Behavior domain. Appendix J displays the item descriptive statistics and specific item-scale correlations corrected for overlap between an item and total score.

Hypothesis 4.5. At time two, 166 participants engaged in the survey. Three participants were excluded from final analysis because over 20% of their data were missing (final n = 163). Participants responded between 14 days and 39 days from initial survey completion (M = 18.83, SD = 5.08, Mdn = 17.0). Test-retest reliability for the domains ranged between 0.48 and 0.98. The specific test-retest statistics are indicated in Table 24. The hypothesis that the CSPro would produce a test-retest reliability of 0.70 or above was supported for approximately 68% of the sub-scales. Appendix K includes the reduced CSPro measure.

Specific Aim 5: To determine which domain of the CSPro has the highest correlation with breast cancer survivors' general self-rated health at time of CSPro administration.

Examination into the single item of general self-rated health indicated that it was normally distributed. The statistical test for normality was significant at $p < 0.0001$; however, skewness and kurtosis were small suggesting that it is appropriate to proceed with the planned analysis of a multiple regression between the total score of each CSPro domain (independent variables) and the single perceived general self-rated health

question (dependent variable). A graph of the distribution of this measure also indicated the normality of this variable (Figure 8).

The overall multiple regression was significant $F(4, 251) = 45.13$, $p < 0.001$, which justified looking at the partial correlations of the four domains with general self-rated health. Function, health services, and health behaviors were not significantly related to general self-rated health ($p = 0.43$, $p = 0.10$, $p = 0.25$, respectively). Symptom burden was significantly associated with general self-rated health (partial correlation $r = 0.40$, $\beta = 0.52$, $p < 0.001$). Hypothesis 5.1 that the health behaviors total score would have the highest correlation with self-rated health was not supported.

Given the poor validity and reliability of the health behaviors domain's exercise sub-scale, the analysis was re-conducted without exercise computed into the health behavior total score. Examination of the findings indicated no significant changes. The overall multiple regression was significant $F(4, 251) = 44.62$, $p < 0.001$. Function, health services, and health behaviors were not significantly related to general self-rated health ($p = 0.54$, $p = 0.06$, $p = 0.72$, respectively). Symptom burden was significantly associated with general self-related health (partial correlation $r = 0.40$, $\beta = 0.53$, $p < 0.001$).

Specific Aim 6: To determine if breast cancer survivors' social desirability, age, and time since completion of primary treatment are significantly correlated with health services, symptom burden, function, and health behaviors at time of initial CSPro administration.

Pearson correlations were conducted between each potential confounding variable and domain sub-scale (Table 25). Anxiety ($r = -0.28$, $p < 0.01$), fear of recurrence ($r = -0.12$, $p < 0.05$), depressive symptoms ($r = -0.20$, $p < 0.01$), cognitive function ($r = -0.19$,

$p < 0.01$), and health competence ($r = -0.16$, $p < 0.05$) were negatively correlated with social desirability. Anxiety ($r = -0.23$, $p < 0.01$), pain ($r = 0.22$, $p < 0.01$), sexual function ($r = 0.15$, $p < 0.05$), diet ($r = -0.29$, $p < 0.01$), and patient-provider communication ($r = 0.24$, $p < 0.01$) were related to age. Anxiety ($r = -0.17$, $p < 0.01$), fear of recurrence ($r = -0.14$, $p < 0.05$), cognitive function ($r = -0.14$, $p < 0.05$), social relationships ($r = 0.23$, $p < 0.01$), and health information ($r = -0.19$, $p < 0.05$) were associated with time since completed active treatment. The final analytic procedure adjusted for social desirability, age, and time since completion of treatment given any significant correlation with the construct, followed by the calculation of standardized scales. Sample standardized scores are displayed in Figure 9. They are plotted using a color-coded bar graph indicating three potential outcomes: MAINTAIN, WATCH, and ACT to guide clinical practice between provider and survivor.

RESULTS SUMMARY

After the principal component analyses, parallel analyses, and tests of validity and reliability, the CSPro was reduced to 76-items. The symptom burden domain has six sub-scales: anxiety, body image, fear of recurrence, fatigue, pain, and depressive symptoms. The function domain has five sub-scales: cognitive function, social relationships, sexual function, sleep, and work. The health behavior domain has three sub-scales: diet, cigarette smoking, and alcohol consumption. The health services domain has four sub-scales: patient-provider communication, health information, healthcare competence, and economic demands.

Chapter IV: Discussion

The present study generated a 76-item clinical assessment tool to measure symptom burden, function, health behaviors, and health services in breast cancer survivors who completed active cancer treatment within the past five years. A multi-method approach was used to select items for the preliminary measure to be called the Cancer Survivor Profile (CSPro). Systematic searches of the qualitative and quantitative literature informed the selection of items from Patient Reported Outcome Measurement Information System (PROMIS) (3) and previously validated measures (20; 45; 74; 101; 180; 246; 281; 334; 360; 368). Researcher-developed items were used when researches did not find items consistent with breast cancer survivors' experiences from these aforementioned sources. This approach is consistent with past measurement development that used mixed methodologies, including classical test theory, to develop self-report measure items (39; 75; 104; 136; 143; 205).

Principal component analyses, parallel analyses, and tests of validity and reliability were used to empirically reduce the preliminary CSPro from 105 items to 76 items. The number of items retained in the final CSPro is due to it being a multi-dimensional measure of 18 constructs across four domains (i.e., symptoms, function, health behaviors, and health service needs). The final CSPro only includes two to six items per construct. The symptom burden, function, and health service domains demonstrated moderate construct validity, substantial convergent validity, and acceptable levels of divergent validity, internal-consistency reliability, and test-retest reliability. There were select sub-scales that performed under these rates for construct validity and test-retest reliability. However, the CSPro showed similar construct validity to other self-

report measures in the breast cancer population (345). The CSPro also has higher test-retest reliability than other measures, such as the Cancer Survivors Unmet Needs' Measure used to assess unmet needs in cancer survivors (205). The health behavior domain demonstrated negligible construct validity, negligible convergent validity, with higher levels of divergent validity, internal consistency reliability, and test-retest reliability. The lower than expected measurement properties of the health behavior domain were largely related to the exercise sub-scale's poor validity and reliability, as well as limitations commonly observed in the area of self-report of health behaviors (159; 238; 297; 331). Therefore, the exercise sub-scale was not retained in the final CSPro.

CSPRO DEVELOPMENT PROCESS

Qualitative and quantitative literature in the breast cancer population was used to identify content and psychometrically sound items for the CSPro. Systematic searches of the qualitative literature (e.g., PubMed, CINAHL, PsychINFO) were conducted to identify what breast cancer survivors' report are common problems in the areas of depressive symptoms, fatigue, anxiety, pain, social relationships, sleep, cognitive function, sexual function, and alcohol consumption. This information was used to select the most common concerns of breast cancer survivors that were available in the PROMIS item bank. PROMIS was utilized because of its large-scale item development and psychometric testing (3). This groundwork has contributed to strong psychometric properties, which have been documented in chronic illness populations including oncology. To identify and select items from non –PROMIS measures, systematic literature searches of quantitative studies that included self-report measures were executed. Identification of self-report measures of fear of recurrence, body image,

cigarette smoking, diet, exercise, weight, health information, health competence, patient-provider communication, economic demands, work, with the highest validity and reliability was conducted.

This combined approach allowed researchers to identify psychometrically acceptable, currently available, and the most applicable items on problems in breast cancer survivors. Items specific to the breast cancer population were generated from multiple sources (i.e., PROMIS, previously validated measures). Other approaches to develop self-report measures such as focus groups, cognitive testing, and expert reviews are available. The approach used in the present study offered an opportunity to use qualitative literature that has formed the cancer survivorship literature to confirm previously existing test items from PROMIS. These other methods for identifying items for measures were not necessary for the current study because patient experiences were directly captured in the qualitative literature and the development of PROMIS items (3; 113). Expert consensus was provided originally in developing PROMIS (3; 113).

The added use of qualitative studies with patient perspectives provided survivor concerns that directly influenced item selection from the PROMIS item database. For example, individuals with a history of breast cancer and cognitive limitations primarily reported problems with memory, concentration, and various aspects of executive function. These findings were consistent with the quantitative studies in the area (383). Breast cancer survivors used similar language across most of the qualitative studies to describe these cognitive problems. Using these qualitative studies as confirmation provided a consistency across studies and insured a degree of clinical significance. This two-stage process of item selection assisted in developing a tool with clinical grounding.

CSPRO DOMAINS

The CSPro measures symptom severity and unmet needs with respect to self-reported symptom burden, functional problems, health behaviors, and health services. The Institute of Medicine outlined these areas as meaningful concerns for evaluation, prevention, and intervention during the survivorship phase of care (216). Symptom intensity (e.g., pain, fatigue, depression) has been negatively associated with quality of life (330). In a heterogeneous sample of 1,822 cancer survivors and 24,804 non-cancer comparisons, a greater percentage of survivors indicated poor physical and mental health (24.5%, 10.1%, respectively) than the non-comparison adults (10.2%, 5.9%, respectively) (382). The CSPro problem areas are associated with health care costs, morbidity, and mortality (129; 198; 203; 233; 342; 371). Excessive alcohol consumption ($\geq$ 6 g/day), increased dietary fat, and absence of physical activity are positively associated with an elevated risk of recurrence, secondary cancers, and other chronic illnesses (82; 119; 233). Cancer survivors have also been shown to have increased use of medical and mental healthcare utilization within the first 5 years post-diagnosis compared to non-cancer matched controls (n =4,444) (124). These cancer survivors had more documented mental health diagnoses (e.g., anxiety disorders, sleep disorders). **The CSPro domains are relevant for screening breast cancer survivors, directing them to the necessary intervention, and potentially reducing healthcare costs**.

CONFIRMATION OF FACTOR STRUCTURE

Each of the principal component analyses resulted in factor structures primarily consistent with the hypothesized factors. This finding supports the conclusion that the CSPro provides a coherent framework for conceptualizing the concerns of breast cancer

survivors. To construct the preliminary CSPro, a systematic approach was used including patient perspectives (i.e., qualitative literature) and scientific data (i.e., gold-standard measures) informing one another. This combined quantitative and qualitative evidence-based approach (323) provided a statistical, theoretical, and patient-centered framework that likely resulted in the CSPro's factor structures with relatively high factor loadings on many items. In addition, the items in the symptom burden, function, and health services factors accounted for a major proportion of variance within each domain, again confirming that the items captured most of what constitutes symptom burden, function and health services needs. In contrast, while still accounting for over half of the variance, the health behavior domain items accounted for the least amount of variance. This finding indicates that health behaviors could be better measured using other items or additional items. This finding may also be related to the fact that only two constructs (i.e., exercise and diet) were subjected to principal component analysis. We could not include alcohol consumption or cigarette smoking in the principal component analysis because they were not applicable to all participants. This methodology is consistent with past measurement development when constructs were not relevant to all participants (400). Future research will need to clarify these potential explanations for the health behavior domain.

PARALLEL ANALYSIS OF CSPRO'S DOMAINS

Parallel analyses were conducted to confirm the principal component analyses. Parallel analysis supported the principal component analysis for the health services domain. It reduced the health behaviors domain as expected, suggesting that the unnamed factor was not a true factor (i.e., it may be due to sampling error). The parallel

analyses also indicated to exclude the depressive symptoms factor (symptom burden domain) and the work factor (function domain). However, these findings need to be considered in light of limitations in parallel analysis. Parallel analysis may identify too few factors (i.e., under factoring) when the first factor contains the most variance or when factors are highly correlated (369). These two attributes were aspects of the symptom burden and function domains in this study. Given that identifying to few factors is more problematic than identifying additional factors (i.e., over factoring) due to loss of information (192) and that depressive symptoms and work have important clinical utility, these factors were retained.

VALIDITY AND RELIABILITY OF CSPRO'S DOMAINS

Psychometric testing supported moderate to substantial construct, convergent, and divergent validity for the CSPro sub-scales. There was evidence for divergent validity of the CSPro sub-scale's fear of recurrence, cognitive function, diet, and health information. These sub-scales distinguish between these concepts and other problem areas. That is, the CSPro sub-scales of fear of recurrence, cognitive function, diet, and health information are unrelated to other measures of different constructs. Items corresponding to CSPro's depressive symptoms, sleep, and patient-provider communication sub-scales positively correlated with gold-standard measures of these problem areas (i.e., CES-D, PSIQ, MPICS, respectively). This finding supports that these sub-scales are measuring constructs similarly to measures with which they are theoretically related.

The principal component analysis and parallel analysis came to different results about retaining the depressive symptoms sub-scale. This sub-scale's substantial convergent validity with the CES-D along with its strong clinical utility provides

additional support to retain it following the results of parallel analysis. There is evidence that this sub-scale is capturing depressive symptoms, a major problem area among breast cancer survivors (398). The exercise sub-scale exhibited poor convergent validity and reliability. Exercise is difficult to capture by self-report (297), which may be responsible for its poor psychometric properties. It is not included in the final CSPro. Removing exercise from the health behaviors domain increased the psychometric properties of the health behaviors domain, as the constructs performed better.

Results revealed strong internal consistency for primarily all sub-scales, suggesting that items on each sub-scale were measuring a similar construct. More specifically, each sub-scale is homogenous in that its items are measuring different aspects of the same construct. Exercise had lower internal consistency reliability than expected, which may be because there are only two items on the sub-scale. Internal consistency reliability (i.e., alpha) decreases with fewer items on a scale (355) and may have affected the current findings. Participant responses over 14 to 39 day duration were stable for the function domain and primarily stable for the symptom burden domain. Health information and health competence, included in the health services domain, still had significant test-retest reliability, but not as high as other sub-scales. This finding indicates greater variability in these constructs over time. The study did not inquire about recent healthcare visits, which may have impacted items related to receipt of health information and health competence. However, it was surprising that these ratings were not as consistent as others over the 2 to 4 week period because there is no evidence that the constructs are not stable. Exercise and alcohol use also had low test-retest reliability.

Health behaviors have poor self-report (159; 238; 331), which may have impacted stability of scores.

FURTHER UNDERSTANDING OF CONSTRUCTS

The consistency between relationships among domain sub-scales and the current literature provide indirect support for the CSPro's construct validity. The moderate positive association of cognitive function with work and sleep is consistent with the body of literature indicating poor sleep is related to lower levels of cognitive functioning (6) and that cognitive impairment is related to work ability (188). However, directionality cannot be assumed from the present study's analyses. The present study also found a moderate positive association between social relationships and work. A similar association was recently documented among a heterogeneous group of cancer survivors (n=1,525). Cancer survivors' self-report of interpersonal work problems (e.g., discrimination, poor treatment, lack of accommodations) was associated with lower work retention and decreased work ability (273). The present study did not differentiate between type of social relationship, but there is an emerging pattern of evidence linking relationships and work problems (273). The CSPro's positive association between economic demands related to cancer and health information, suggests that breast cancer survivors with greater financial strain also have lower access to cancer-related information. Prior research has found that cancer survivors with lower income (>$25,000/year) are less likely to seek cancer related information (254). Although this finding needs to be further confirmed in future studies, it has important implications to receipt of health services needs among breast cancer survivors. There was also a

substantial association of fatigue with pain, depression, and anxiety, consistent with previous research in cancer survivors (42).

The present study's observed association of depressive symptoms and pain is consistent with past research on pain (339; 370). Prospective research also indicates that depression is a significant predictor of pain in breast cancer survivors one year post-primary treatment (370). These findings are consistent with the Gate Control Theory of pain, and more recently the neuromatrix of pain, which postulates that depressive symptoms increase pain perception (258; 259). In terms of potential clinical implications, the findings that a single intervention can target multiple symptoms (148) may facilitate improvement in both pain and depression. The use of exercise (121; 302) or serotonin and norepinephrine reuptake inhibitors (219) can reduce both symptoms.

Correlations among sub-scales provided evidence for the hypothesis of symptom clusters (86; 263). The high correlations among certain sub-scales within the symptom burden domain support the symptom cluster hypothesis among breast cancer survivors. Fatigue, anxiety, cognitive function, sleep, pain, and depressive symptoms are problem areas that emerge as clusters of symptoms (272; 316; 401). Research indicates that cancer patients that have higher symptom clusters (e.g., greater number of symptoms) prior to treatment continue to have higher symptom clusters during active treatment (239). Higher symptom clusters in survivorship are associated with decreased quality of life (330). It is hypothesized that there is a shared biological etiology among these symptoms, such as proinflammatory cytokines, which produce a constellation of behavioral symptoms (86; 263). However, to date there is limited evidence concerning this biobehavioral mechanism of symptom clusters.

Certain problem areas have been shown to improve as time from initial diagnosis increases (18; 112). In the present study anxiety, fear of recurrence, cognitive function, and health information were found to be negatively associated with time from active treatment, providing confirmatory data on the relationship between time since completion of active treatment and symptom severity. However, in the present study it was observed that higher levels of social strain were related to duration of survival. Breast cancer survivors commonly express that social support declines following the end of primary treatment when support systems expect survivors' physical and emotional levels to return to pre-diagnosis levels (54; 163). The discordance between survivors' actual social experiences and expectations could contribute to strained relationships. The understanding of social function in breast cancer survivors needs further study.

PERCEIVED GENERAL HEALTH

Symptom burden was the only domain significantly correlated with perceived general health. This finding is inconsistent with the study's original hypothesis that health behaviors would be most highly associated with perceived general health in breast cancer survivors. Notwithstanding some of the measurement concerns with the health behavior domain, it is understandable that breast cancer survivors' mood symptoms (e.g., anxious and depressed mood, fear of recurrence) and physical symptoms (e.g., pain, fatigue) would be related to how they view their health and well-being. A previous study investigated the association among self-reported diseases (e.g., neurological, cancer, rheumatoid arthritis) and symptoms (e.g., depression, tiredness/weakness) with general self-rated health in a sample of adult men and women (N = 6,061) (267). Depression and tiredness/weakness were among the factors to have the highest positive contributions to

general self-rated health. Also, the risk for reduced ratings in general self-rated health has been shown to increase with frequency of pain symptoms (247). These symptoms are among those measured in the CSPro's symptom burden domain. Currently, there is limited research examining self-rated health in the cancer survivor population. Future research will need to further examine the association between self-rated health and outcomes (e.g., symptoms, health behaviors, function, health service needs) in the cancer survivor population to understand if it maintains a similar relationship as seen in the general population.

INTEGRATION OF CSPRO INTO ONCOLOGY AND PRIMARY CARE

Breast cancer survivors can experience multiple problems in the areas of health, healthcare, function, and well-being. Some of these problems can persist years post active treatment at clinical and sub-threshold levels affecting function, quality of life, and disease states (190). At present while improvements in follow-up care are occurring, most cancer survivors continue to be left on their own following cancer treatment. The problems experienced by breast cancer survivors may benefit from a more comprehensive, yet brief evaluation using clinically and psychometrically valid and reliable assessment. Currently, most cancer-related self-report measures are focused on one problem or a few problems, developed in breast cancer patients during active treatment, or intended for research purposes (40; 47; 345). The applicability of these measures to breast cancer survivors in clinical settings is unclear (242). Given that time is a barrier in survivorship care planning (349), it is often not feasible to provide breast cancer survivors with the original self-report measures of various problem areas within a medical appointment. Also it was observed that in cancer survivor clinics, medical

information is more likely to be documented for the survivor than psychosocial or health promotion/prevention information (349). Related to this finding, the psychosocial working group of the National Cancer Institute Community Cancer Center Program (NCCCP) examined the use of existing standardized assessment tools for screening of psychosocial problems in cancer survivors at NCCCP sites (N = 30) (153). In 2010 there was a lack of use of these psychosocial screening surveys at these sites, with only 12.5% sites using a standardized assessment tool and only 31.3% of sites using a standardized screening tool along with a comprehensive assessment. The **CSPro is a unique addition to survivorship care planning** because it takes into account these current limitations and needs. The CSPro **provides a simple multi-dimensional assessment of actionable problem areas**. It serves as **a potentially cost effective tool** for triage to targeted interventions and resources, and to **provide ongoing surveillance** of problem areas among breast cancer survivors.

Tools in survivorship care planning

Survivorship Care Plans

The American College of Surgeons Commission on Cancer mandated that all accredited Commission on Cancer programs use Survivorship Care Plans by 2015 (88). Cancer survivors and providers agree that Survivorship Care Plans should be incorporated into care to improve health, well-being, and coordination of care (196; 248). Primary care providers who routinely receive Survivorship Care Plans for their patients indicate better coordination of care, communication with physicians, and having knowledge about medical and psychosocial survivorship concerns than those who do not routinely receive them (N =1,020) (152). However, recent data indicate that only

approximately 20% of oncologists provide Survivorship Care Plans to survivors (152). Barriers to their implementation include perceived amount of time to complete, reimbursement issues, and overall poor cost effectiveness (100; 217; 349). Also, a recent randomized control trial found that Survivorship Care Plans failed to effect patient satisfaction, mood, distress, and coordination of care (182).

Currently, there are limitations that may prevent Survivorship Care Plans from fully improving survivorship outcomes. Despite these limitations consumer and provider demand for Survivorship Care Plans remains (196; 248). Patient-centered care and evidence-based medicine incorporates patient preferences (217), and it is important to continually integrate these perspectives into how the CSPro will be used. **Providers can use the CSPro to augment Survivorship Care Plans**. The CSPro will allow Survivorship Care Plans to focus on survivors' most significant problems, triage care, and in the process may contribute to reduction in overall time and costs spent on Survivorship Care Plans.

Treatment summaries

Additional research needs to investigate Survivorship Care Plans feasibility and effectiveness in clinical practice. Given the uncertainty of Survivorship Care Plans' validity, exploring other clinical uses of the CSPro is warranted. Treatment summaries are another option. **The CSPro provides a comprehensive evaluation of non-medical late and long-term consequences of cancer**. Providers may use the CSPro alongside a treatment summary to coordinate care of breast cancer survivors' medical and non-medical cancer survivorship needs. Primary care providers express that receipt of treatment summaries support a shared care model of survivorship (225).

Current breast cancer surveillance guidelines outline a shared-care model of survivorship between the oncologists and primary care providers (224). To facilitate continuity of care, primary care providers are to manage follow-up care and refer survivors to an oncologist for assessment when needed. A recent nationally representative study of primary care providers (n =1,014) and oncologists (n =1,1125) suggests a discrepancy between primary care providers and oncologists provision of survivorship care for breast cancer survivors (225). The majority of oncologists (79%) reported solely fulfilling the role, while approximately 40% of primary care providers indicated participating in a shared-care model of survivorship care with oncologists. Interventions and clinical assessment tools are needed to support communication and a shared-care model of survivorship. Receipt of treatment summaries is positively associated with primary care providers co-managing survivors' care with oncologists (225). Providing primary care providers with **the CSPro** output (Figure 9) **may also facilitate communication and coordination of survivorship problems**. Primary care providers will have the relevant information to directly assist in the treatment of the most significant problem areas for their patients.

Cancer survivor nurse navigators

Multi-disciplinary approaches to survivorship care also include nurse practitioners and nurse navigators. Nurse navigators are considered central to coordination of services as there will be a shortage of oncologists and primary care providers as the number of survivors increase (217). The CSPro aligns with the type of care nurse navigators provide. Nurse navigators connect cancer survivors to services that assist with survivors' care, financial stability, and emotional and physical well-being. **The CSPro can alert**

nurse navigators to the type of services that breast cancer survivors are most in need of receiving.

ADVANTAGES OF ELECTRONIC ASSESSMENT TOOLS

Breast cancer survivors' tendency to not discuss cancer-related concerns with their providers is negatively associated with quality of life and positively associated with pain interference (127). Cancer survivors have expressed concern that discussing their problems will jeopardize patient-provider relationships (318). Social desirability was negatively associated with some CSPro sub-scales (e.g., anxiety, depressive symptoms, cognitive function, health competence), providing some additional clarity about report of problem areas. Surprisingly, CSPro diet was not related to social desirability as it has been in previous research (194). There was no significant relationship between social desirability and CSPro patient-provider communication, which may be related to the anonymity of an Internet study. **The CSPro will eventually be administered electronically on a tablet or other mobile device**. There is evidence from cancer patient populations to support electronic assessment tools use in evaluation of symptoms and improvement of patient-provider communication (30; 199). A heterogeneous sample of cancer patients (n =295) randomized to an intervention arm completed an electronic assessment measure about symptoms and quality of life (30). The graphical output was given to patients' providers and results indicated that there was an increase in positive patient-provider communication about symptoms between the intervention's patients and providers as compared to the control group (n = 295).

Breast cancer survivors' unmet needs are associated with depression and decreased quality of life (290). Psychological and health system/information needs decrease as survival duration increases (55; 290). In a large sample of breast cancer survivors (N=1,084), those 1 year post-surgery reported the greatest unmet needs, followed by those 3-5 years post-surgery, and finally those > 5 years post-surgery (290). Survivors > 5 years following surgery still reported significant problems associated with depression and decreased quality of life, which suggests that ongoing monitoring is needed. Breast cancer survivors express preference for an electronic communication aid (i.e., Survivorship Care Plan) to be continually updated with changes in their physical and psychosocial status (336). The CSPro incorporates these elements. It is important to monitor symptoms to prevent symptom chronicity. Symptoms persisting for more than ten years post-active treatment affects quality of life (190; 231). **The CSPro can aid in early detection, monitoring, and triage to reduce symptom burden and functional limitations**. Use of the CSPro via electronic methods in clinical practice will need to be made Health Insurance Portability and Accountability Act compliant using the medical center's standard practices.

LIMITATIONS

The current study has limitations. The study was cross-sectional so directionality cannot be assumed from correlations. Not all problem areas relevant to breast cancer survivors were included in the CSPro. The CSPro included the most prevalent problem areas based on the scientific literature and framework of cancer survivorship care (216). The CSPro was designed with consideration to current limitations in cancer survivorship care planning, such as time barriers to identify problem areas and triage to further level of

care. Therefore, a brief measure to prevent survivor/provider burden was created. The CSPro only focuses on problem areas, rather than on positive effects of cancer (e.g., benefit finding) to better allow for intervention and improvement of late and long-term effects of cancer. Other variables that can influence breast cancer survivors' overall well-being (e.g., coping) were not included. Some breast cancer survivors may experience negative coping strategies (e.g., avoidant coping). However, it was reasoned that if these coping strategies are problematic, then they will likely manifest in other problem areas included in the CSPro (e.g., depression, anxiety). Therefore, if an associated factor is elevated, then the coping strategy will also be considered and targeted with the intervention. Moreover, while breast cancer survivors' stage of change may influence health behavior outcome (298), assessment of stages of change was not be conducted in the CSPro to reduce patient and provider burden. Providers who conduct further interventions can evaluate the stage of change if needed (e.g., lack of progress toward health behavior change).

There was a potential bias in selection of the CSPro items. The item selection process included three reviewers. Reviewer One was the principal investigator and Reviewer Three was the Principal Investigator's Major Advisor. To reduce the potential for bias, Reviewer Two was not associated with the proposed study. Also, strict criteria were used to select items. All data collected were self-report. No direct observation of behaviors (e.g., cigarette smoking, physical activity/exercise) was made. However, self-report measures that were validated by behavioral observation or physiological measurement were selected when possible. Because of the online study, medical data were self-reported. However, self-report of medical information is consistent with that

documented on medical charts (251). While efforts were taken to recruit a representative sample of breast cancer survivors that are similar to national figures (e.g., race, ethnicity), the study employed a convenience sample. The study sample was primarily Caucasian breast cancer survivors. This majority of studies in breast cancer are not representative of the breast cancer population by race and ethnicity (35). Caution is needed when extrapolating the present results to the entire breast cancer survivor population.

Data collection via the Internet enabled for breast cancer survivors across the United States to complete the study. The study material was available for participants to complete at their convenience, and reduced study costs (e.g., paper, mailing cost). The final version of the CSPro is intended to be administered electronically to expedite the scored profile for clinical use (i.e., to identify problems areas or potential problem areas that need clinical care). For that reason, the development of the CSPro was tested using an electronic survey tool and the Internet to obtain the data.

There are potential limitations to data collection over the Internet, including respondent bias. However, a study on a recent ten-year period (i.e., 2002-2012) indicated that the percentage of Americans using search engines increased from 52% to 73% (299). Yet, an Internet-based study may be subject to selection bias (32). While at this point in time 69% of cancer survivors are Internet users (372) these users were less than 60 years of age, well educated, and had a relatively higher socio-economic status The majority of participants in the present study were between the ages of 51 and 78 indicating a broader range of ages than in many previous Internet surveys. However, the sample was a relatively well educated group (i.e., associate's degree or higher).

Participants responded to the second administration of the CSPro (i.e., to examine test-retest reliability) at different points of time, potentially due to the flexibility of an Internet survey. Also, participants with questions about the study material did not receive immediate answers. Participants received a study phone number and study email address to contact the study's principal investigator about questions or concerns. Internet research's dropout rate is higher than laboratory research (32), which may be because of the anonymity of this method (e.g., not appearing in person). Having participants provide personal information may have lowered the dropout rate (9.2%) because they were more identifiable. This method may have accounted for the low dropout rate for the present study.

The review of quantitative self-report measures on body weight was not successful in identifying a self-report measure of weight that was reliable and valid. Studies consistently abstracted body mass index from medical charts or used self-report of height and weight to compute body mass index (BMI). Self-report of height and weight is well-known to be inaccurate, with a tendency for individuals to over report height and underreport weight (89; 282). The CSPro will primarily be used in a clinical context; and, BMI can be computed from direct measures of height and weight. Given the availability for measuring weight in the clinical context, there was no rationale to include height and weight (BMI) in the CSPro. A place marker is used in the CSPro output (Figure 9) for providers to enter survivors' BMI. Inclusion of BMI is important for continual evaluation and triage given association of increase in weight and functional limitations (397), recurrence, and disease-free survival (314).

STRENGTHS AND CLINICAL IMPLICATIONS

The study conceptualization and implementation have strengths that should benefit the CSPro in clinical practice. The CSPro assesses symptom burden, health behaviors, function, and health service needs. It also models delivery system design within the framework of the Chronic Care Model by facilitating productive interaction about patient information between multidisciplinary team members (377; 378). The CSPro can facilitate assignment of care from one treating provider to another appropriate provider. The CSPro provides a platform as a decisional support tool to improve quality care within evidence based medicine through the reduction of decision making errors (23). The feasibility and effectiveness will need to be tested in future studies. Also, in the framework of cancer survivorship care, the CSPro should help promote a shared-care model of cancer survivor care.

Design and evaluation of the CSPro's psychometric properties followed scientific criteria for health status and quality of life measures (242). Multiple methods were used to construct the CSPro, including the most recent evidence, patient experiences, and valid measures of problem areas. Accepted methods of determining test scales' reliability and validity (e.g., construct, convergent, divergent) were followed. Tests demonstrated sub-scales' measurement properties for breast cancer survivors. Each breast cancer survivor's output can be individually adjusted for age, time since completion of active cancer treatment, and social desirability, when relevant. This methodology allows for a more accurate assessment of breast cancer survivors' experience with the problem areas.

Major areas of consistent concern in cancer survivorship care that are typically not systematically and efficiently addressed in many current Survivor Care Plans are included in the CSPro. These areas can now be integrated in survivorship care planning

(e.g., augment Survivorship Care Plans, nurse navigators). The CSPro uses a simple transportable electronic assessment method for measuring concerns breast cancer survivors have reported both in qualitative and quantitative research. This aspect of the present research makes the CSPro consistent with evidence-based health care (323). The CSPro also provides a simple to understand graphic output allowing survivors and providers to identify current problem areas and to refer breast cancer survivors to health care, self-care, or informational interventions. The utilization of the CSPro may improve provider-patient communication through its potential as a communication aid (377; 378). The overall process described in this doctoral dissertation study provides a sound methodological and statistical foundation for the future study of the clinical validity of the CSPro in various types of clinical settings.

FUTURE RESEARCH

The present study focused on the development and determination of the CSPro's initial psychometric properties in breast cancer survivors within five years duration of active treatment. There is also justification to use the CSPro in adult and childhood survivors of other malignancies. Constructs included in the CSPro are main problem areas for other cancer survivors, and have been associated with morbidity and mortality with these populations (97; 190; 371). There may be some variation among symptoms between survivor type (e.g., type of body image concern). The CSPro is intended to be a general delivery system design measure and does not assess problem specificity so this is not of concern. The CSPro was comprised of items based on the breast cancer population literature. Therefore, qualitative and quantitative studies need to be conducted to determine the content validity and overall generalizability for other survivor populations.

The present study focused on the development of the CSPro and establishment of its initial psychometric properties using classical test theory. Additional testing of the psychometric properties could be conducted with a different measurement technology, such as item response theory. Item response theory can be utilized with classical test theory to examine a measure's differential item functioning (98; 186). This analysis can detect differences between groups of different variables (e.g., age) and adjustments can be made to individual items (e.g., removal of item). The current study adjusted for confounders' contributions with a different method.

CONCLUSION

This doctoral dissertation project produced the Cancer Survivor Profile (CSPro). The CSPro is a 76-item, multi-dimensional measure of symptoms, function, health behaviors, and health service needs. Across the four domains, eighteen sub-scales were identified. The symptom burden domain includes six sub-scales (i.e., anxiety, fatigue, pain, body image, fear of recurrence, depressive symptoms). The function domain includes five sub-scales (i.e., cognitive function, social relationships, sleep, sexual function, work). The health behavior domain includes three sub-scales (i.e., diet, cigarette smoking, alcohol consumption). The health services domain includes four sub-scales (i.e., patient-provider communication, health information, healthcare competence, economic demands). The CSPro can be an integral addition to survivorship care planning. It may assist in the detection, monitoring, and triage of problem areas to reduce symptom burden and functional limitations in breast cancer survivors.

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Table 1. Measures

Measure	Cancer Diagnosis	Years Post Diagnosis (Mean)[1]	Sample Size	Number of Items	Sub-scales	Analyses
Cancer Patients						
European Organization for Research and Treatment of Cancer QLQ-C30 (EORTC QLQ-C30) (1)	Non-ressectable Lung Cancer (Patients from 13 countries)	Before treatment and during treatment	305	30	Functional Scales: Physical, Role, Cognitive, Emotional, Social Symptom Scales: Fatigue, Pain, Nausea and vomiting Global Health and Quality of Life Scale	*Validity*: Multitrait scaling (convergent and discriminant validity), inter-scale correlations, clinical validity (known-group comparisons, responsiveness to change in health status) *Reliability*: Internal Consistency
The Functional Assessment of Cancer Therapy-Breast (47)	Breast Cancer	Patients with breast cancer	Sample 1: 47 Sample 2: 295	44	Multidimensional quality of life: Physical well-being, Emotional well-being, Social well-being, Functional well-being, Relationship with doctor, Breast cancer sub-scale	*Validity*: Sensitivity to change*, construct, discriminant *Reliability*: Internal consistency, test-retest reliability * Sample 1, all other analyses conducted on Sample 2
Long-Term Cancer Survivors						
The Quality of Life-Cancer Survivors (136)	Breast, Lymphoma, Ovarian,	6.8	686	41	Physical, Psychological, Social, Spiritual	*Validity*: Content, predictive, concurrent, principal component factor analysis

	Hodgkins, Cervical, Leukemia, Colon, Other (Male & Female)					*Reliability*: Test-retest, internal consistency
Long-Term Quality of Life (395)	Female cancer survivors	8.42 "years of survival"	187	70	Physical, Psychological, Social, Spiritual	*Validity:* Factor analysis (Type not specified but appears to be principal component factor analysis)
Impact of Cancer (400)	Breast, Prostate, Colorectal, Lymphoma (Male & Female)	7.67	193	70	Physical, Psychological, Social, Spiritual/existential, Miscellaneous	Qualitative Interviews *Validity*: Content, construct, concurrent, discriminative, exploratory factor analysis, multi-trait multi-item analyses *Reliability*: Internal consistency
Impact of Cancer Scale version 2 (101)	Breast cancer (Female)	7.4	1188	47 (Prim-ary: 37, Second-ary: 10)	Positive Impact Summary scale: Altruism and empathy, Health awareness, Meaning of cancer, Positive self-evaluation Negative Impact Summary scale: Appearance concerns, Body change concerns, Life interferences, Worry	*Validity:* Exploratory factor analysis, split-sample cross validation (randomly split sample to determine reproducibility of exploratory factor analysis), construct, concurrent, face *Reliability*: Internal consistency reliability

					Secondary Scale: Employment and relationship impacts	
Physical Symptoms						
The Breast Cancer Prevention Trial Symptom Scales (345)	Sample 1: Breast cancer stage 0-II Sample 2: Breast cancer stage 0-II Sample 3: Breast cancer Stage I-II Sample 4: At risk for breast cancer	Sample 1: 1-5 years Sample 2: 2-10 years "disease free" Sample 3: "Recently completed medical treatment" for breast cancer Sample 4: NA	Sample 1: 863 Sample 2: 577 Sample 3: 560 Total: 2208 Sample 4: 208	42	Hot flashes, Nausea, Bladder control, Vaginal problems, musculoskeletal pain, Cognitive problems, Weight problems, Arm problems	*Validity*: Exploratory factor analysis, parallel analysis (Sample 1); confirmatory factor analysis, discriminant (Samples 2-4) *Reliability*: Internal consistency
Needs Surveys						
Supportive Care Needs Survey (39)	Breast, Colon and Rectum, Prostate, Skin/Melanoma, Don't know, Other (Male and	Diagnosed at least 3 months prior to study (majority of participants	888	54	Psychological, Health system and information, Physical and daily living, Patient care and support, Sexuality	*Validity*: Exploratory factor analysis, face, content *Reliability:* Internal reliability coefficients

	Female; New South Wales, Australia)	were in current treatment)				
Supportive Care Needs Survey Short-Form (SCNS-SF34) (45)	Breast, Colorectal, Prostate, Lung, Other (Male and Female)	Sample 1: Diagnosed at least 3 months prior to study (majority of participants were in current treatment) Sample 2: Did not specify	Sample 1: 888 divided into 1a *n* =444, 1b *n* = 444 (39) Sample 2: 250	34	Psychological, Health system and information, Physical and daily living, Patient care and support, Sexuality	Sample 1 divided into 2 (1a *n* =444, 1b *n* = 444). *Validity:* Exploratory factor analysis (sample 1a), confirmatory factor analysis (sample 1b), convergent (sample 2) *Reliability*: Internal (sample 1b)
Cancer Survivors' Unmet Needs (CaSun) (205)	Breast, Gynecologic, prostate, Colorectal, Other (Male and Female)	1 to 15 years post-diagnosis	353	41 + 1 open ended question	Existential survivorship, Comprehensive care, Information, Quality of life, Relationships	*Validity*: Exploratory factor analysis, face, content *Reliability*: Internal consistency, test-retest reliability

[1]Unless otherwise noted.

Table 2. Survivorship Care Plans

	American Society of Clinical Oncology (14) American Society of Clinical Oncology	**Journey Forward** (221) National Coalition for Cancer Survivorship, UCLA Cancer Survivorship Center, Wellpoint, Inc., Genentech	**Lance Armstrong Foundation** (234) Lance Armstrong Foundation	**Prescription for Living** (296) American Cancer Society, Oncology Nursing Society, National Coalition for Cancer Survivorship, American Journal of Nursing, University of Pennsylvania School of Nursing
Health Services				
Health Information	X	X	X	X
Health Care Access	X	X	X	X
Communication	X	X	X	X
Economic Barriers	X	X	X	X
Symptoms				
Fatigue	X	GR	"Are you experiencing fatigue (overwhelming physical, mental or emotional exhaustion)?"	"Persistent fatigue"
Depressive Symptoms	X	X	X	"Major depression" "Depression"
Anxiety	X	X	X	"Anxiety disorder" "Anxiety"
Pain	GR	GR	"Development of pain, numbness or tingling in the arm on the side of the surgery?" "Pain, numbness or tingling of the arm on the side of the radiation?"	"New pain (bone, abdomen, head and neck)
Fear of Recurrence	X	X	X	X
Body Image	X	X	"How would you rate the cosmetic appearance	X

			of the affected breast compared to your other breast?" "Do you have changes in the color or texture of your skin as a result of radiation therapy?"	
Fertility Distress	X		GR	X
Function				
Social Relationships	X	X	X	X
Work	X	X	X	X
Sexual Function	X	GR	"Experience sexual changes (vaginal dryness, shrinkage, painful intercourse)?"	"Psychosexual problems"
Cognitive Function	X	GR	X	X
Sleep Disturbance	X	X	X	"Sleep problems"
Health Behaviors				
Smoking	X	X	GR	"Smoking cessation"
Alcohol Consumption	X	X	GR	X
Physical Activity	X	X	GR	"Physical activity"
Diet	X	X	GR	"Nutrition and healthy weight management"
Weight Change	X	"Patient's BMI Pre-treatment Post-treatment" "Patient's Weight Pre-treatment Post-treatment"	GR	"Weight gain > 10 lbs" "Weight loss > 10 lbs" "Nutrition and healthy weight management"

X = Not addressed; GR = General recommendations in Survivorship Care Plan

Table 3. Psychometric properties

Validity			
Type	Description	Rating	Statistical Tests
Content validity (156; 400)	Measures the correct content and is representative of the factors comprising the construct. Includes face validity.	Qualitative rating	Experts in the field and participants review of scale
Criterion validity (156)	Scale's ability to predict a criterion variable. The scale's level of agreeing with an external measure.	Patient reported outcomes usually do not have a standard. Therefore, criterion validity is not relevant to patient reported outcomes.	Sensitivity and specificity
Construct validity (56)	How well scale represents theoretical understanding of construct.	Negligible association: $\|r\| < 0.30$ Moderate association: $0.30 < \|r\| > 0.45$ Substantial association: $0.45 < \|r\| > 0.60$ Strong association: $\|r\| > 0.60$	Spearman correlations among subscales Pearson product-moment correlations among subscale scores (Continuous: correlation coefficients; Categorical: analysis of variance)
Convergent and divergent validity (56; 59)	Type of construct validity. Whether items on a scale represent construct intended to be measures rather than another construct.	Negligible association: $\|r\| < 0.30$ Moderate association: $0.30 < \|r\| > 0.45$ Substantial association: $0.45 < \|r\| > 0.60$ Strong association: $\|r\| > 0.60$	Multitrait-Multimethod matrix
Exploratory factor analysis (307)	Type of construct validity. Factor validity.	Low loading items (< 0.40) or items that load on	Exploratory factor analysis

		multiple factors at > 0.40 removed	
Confirmatory factor analysis (149)	Type of construct validity. Item distinctiveness/ discrimination across scales.	Constricting factors to load on factors derived from exploratory factor analysis.	Structural equation modeling
Reliability			
Type	Description	Rating	Statistical Tests
Internal consistency reliability (91; 156; 287)	Items on a scale are measuring a similar construct. It is desirable to have high correlation among a subtest's items.	Reliable if $\propto > 0.70$	Cronbach's coefficient $\propto$ tested with a two-way fixed-effect ANOVA that differentiates the "signal" (between subject variance) from the "noise" (interaction between subjects and different item responses)
Test-retest reliability (307)	Temporal stability	Pearson's correlation coefficient, ranges from -1 to 1	Reliability coefficient

Table 4. Scientific Advisory criteria for health status and quality of life measures*

Component	Definition	Examples of Review Criteria
Conceptual and measurement model	Explanation of concept. Intended population for measurement use.	Empirical and conceptual evidence for test items. Consideration of target population perspective on item inclusion.
Reliability	Degree of random error. Includes internal consistency (instrument's precision) and reproducibility (test-retest reliability and inter-rater reliability)	Internal consistency: Reliability estimates and standard errors; reliability coefficients Reproducibility: Interclass correlation coefficients of test-retest reliability and inter-rater reliability; Rationale for time interval between first administration and second administration (i.e., for test-retest reliability)
Validity	Measurement of what instrument is intended to assess. Includes content-related validity, construct-related validity, and criterion-related validity.	Rationale for choice of criteria measures. Description of method to test validity.
Responsiveness	Sensitive to change over time.	Longitudinal data with comparison of group that is predicated to change against group that is predicted to remain stable.
Interpretability	Ease of understanding the instrument's quantitative scores.	Description of how to interpret the scores (e.g., cut-off points).
Burden	Inconvenience to the administrators and respondents.	Administrator: Resources and training needed to administer measure. Respondent: Description about amount of time it takes to complete instrument, reading comprehension level needed to understand directions and

		items, and consideration of emotional and physical burden to complete measure.
Alternate modes of administration	Interview-administered, self-report, computer-assisted, etc.	Psychometric properties of alternative modes of administration.
Cultural and language versions	Conceptual and linguistic likeness.	Description of methods to establish conceptual and linguistic equivalence.

*Table 4 is adapted from material presented in Table 1 of Scientific Advisory Committee (327)

Table 5. Targeted enrollment

Ethnic Category	**Target Participants (n)**	**Target Participants (%)**	**Actual Participants (n)**	**Actual Participants (%)**
Hispanic of Latino	31	12%	17	6.6%
Not Hispanic or Latino	228	88%	239	86.8%
Racial Category	**Target Participants (n)**	**Target Participants (%)**	**Actual Participants (n)**	**Actual Participants (%)**
American Indian/Alaska Native	2	1%	4	1.6%
Asian	10	4%	5	1.9%
Native Hawaiian or Other Pacific Islander	1	0%	1	0.4%
Black or African American	34	13%	17	6.6%
White	212	82%	224	86.8%

Note. Not all categories equal N= 259 or 100% due to missing data.
Target number and percentage derived from breast cancer incidence adjusted for race and ethnicity.

Table 6. Item constructs included in PROMIS database

Health Services	Symptom Burden	Function	Health Behaviors
Health information	Fatigue*	Cognitive limitations*	Smoking
Health competence	Depressive symptoms*	Social relationships*	Alcohol consumption*
Communication	Anxiety*	Sexual function*	Physical activity/exercise
Economic demands	Pain*	Sleep*	Diet
	Fear of recurrence	Work problems	Weight change
	Body image		
	Fertility distress		

*Items covered in PROMIS

Table 7. Inter-rater agreement for each domain covered in systematic search: PROMIS

Construct	Agree/Total Articles	Percent Agreement
Fatigue	109/129	84.5
Pain	84/102	82.35
Depression	144/165	87.27
Anxiety	134/149	89.93
Cognitive function	109/117	93.16
Sleep	135/137	98.54
Sexual function	169/183	92.35
Social relationships	513/550	93.27
Alcohol abuse	56/56	100
	Average Percent Agreement	*91.26*

Table 8. Inter-rater agreement for each domain covered in systematic search: Non-PROMIS

Non-PROMIS Inter-rater reliability		
Construct	Agree/Total Articles	Percent Agreement
Body image	118/131	90.08
Patient-provider communication	223/249	89.56
Diet	301/388	77.57
Economic demands	1031/1060	97.26
Exercise/physical activity	194/225	86.22
Fear of recurrence	920/1028	89.49
Fertility distress	206/207	99.51
Health information	863/907	95.15
Healthcare competence	525/550	95.45
Smoking	91/127	71.65
Weight	251/269	93.31
Work function	109/123	88.62
	Average Percent Agreement	89.49

Table 9. Demographics (n = 259)

	N	%	M	SD
Age				
≤ 40 years old	37	19.9	49.73	11.1
41-50 years old	63	33.9		
51-78 years old	86	46.2		
Race				
Caucasian	224	86.8		
Black or African American	17	6.6		
Asian	5	1.9		
American Indian/Alaska Native	4	1.6		
Native Hawaiian or Other Pacific Islander	1	0.4		
Other	5	1.9		
Ethnicity				
Non-Hispanic	239	92.6		
Hispanic or Latino	17	6.6		
Education				
Less than high school	1	0.4		
High school	20	7.8		
Some college	50	19.4		
Associate's degree	22	8.5		
Bachelor's degree	63	24.4		
Some graduate school	34	13.2		
Graduate degree	67	26		
Household Income				
0-39,000	58	23.8		
40-59,000	45	17.4		
60-79,000	43	16.7		
80-99,000	28	10.9		
100,000 or more	70	27.1		
Employment Status				
Unemployed (by choice)	54	20.9		
Unemployed (not by choice)	21	8.1		
Employed part-	40	15.5		

time				
Employed full-time	139	53.9		
Marital Status				
Single	27	10.5		
Single, cohabitating	11	4.3		
Married	163	63.2		
Divorced	48	18.6		
Widowed	8	3.1		

Note. Not all categories equal N= 259 due to missing data; M = $\bar{x}$

Table 10. Medical history

	N	%	
Tumor Location			
Right breast	120	46.5	
Left breast	121	46.9	
Both breasts	15	5.8	
Tumor Stage			
I	99	38.4	
II	108	41.9	
III	49	19.0	
Treatment			
Chemotherapy	192	74.4	
Radiation	179	69.4	
Surgery	256	99.2	
Adjuvant treatment	152	59.4	
Menopausal Status			
Pre-menopausal prior to cancer, pre-menopausal after cancer treatment	70	27.1	
Pre-menopausal prior to cancer, post-menopausal after cancer treatment	95	36.8	
Post-menopausal before cancer diagnosis or treatment	91	35.3	
Years Since Primary Treatment			
0 - 1 year	74	34	M (SD)
< 1 and ≥2 years	47	19.6	1.99 (1.43)
< 2 and ≥ 3 years	47	19.6	Mdn = 1.83
< 3 and ≥ 4 years	38	15.6	
< 4 and ≥ 5 years	27	11.2	

Note. Not all categories equal N= 259 due to missing data; M = $\bar{x}$

Table 11. Pattern matrix (factor loadings) for the symptom burden domain

Symptom Burden Domain Item	Factor 1 "Anxiety"	Factor 2 "Pain"	Factor 3 "Fear of Recurr-ence"	Factor 4 "Body Image"	Factor 5 "Fatigue"	Factor 6 "Depre-ssive Symp-toms"
Total Percent Variance, 73.90%						
Anxious	**0.89**	-0.49	0.15	-0.06	-0.01	0.11
Tense	**0.78**	0.02	0.05	0.12	-0.03	0.02
Emotional	**0.71**	0.01	-0.03	0.00	-0.03	-0.13
Irritable	**0.68**	-0.01	-0.10	0.13	-0.10	-0.05
Fearful	**0.67**	0.05	0.14	-0.06	0.13	-0.21
Tearful	0.64	-0.02	-0.02	0.02	-0.09	-0.30
Worries	0.60	-0.02	-0.02	0.02	-0.09	-0.30
Severe	0.00	**0.93**	-0.04	0.00	0.03	0.01
Interfere	-0.04	**0.91**	0.03	0.05	0.02	-0.01
Joint	-0.03	**0.84**	0.10	-0.11	0.02	-0.01
Daily activities	-0.03	**0.81**	-0.03	0.05	-0.14	-0.02
Burning	0.03	**0.81**	-0.03	0.05	-0.13	-0.02
Cancer unsure	0.01	0.07	**0.84**	-0.01	-0.01	-0.05
Coming back	-0.03	-0.12	**0.82**	0.03	-0.09	-0.00
Cancer health	-0.02	0.05	**0.82**	-0.01	-0.08	-0.06
Worry future	0.12	0.08	**0.80**	0.04	0.01	0.00
Worry health	0.09	0.05	**0.77**	0.10	-0.02	0.03
New symptoms	-0.04	-0.08	**0.75**	0.04	0.05	-0.08
I felt worried	0.38	0.17	0.44	-0.08	-0.12	-0.08
Cover body	-0.01	-0.03	0.01	**0.89**	-0.03	0.03
Disfigured	-0.06	0.00	0.02	**0.85**	0.01	-0.13
Body looks	0.08	0.08	0.11	**0.82**	0.02	0.01
Fatigued	-0.02	-0.01	0.06	-0.05	**-0.91**	-0.90
Run-down	-0.05	-0.03	0.06	-0.00	**-0.87**	-0.13
Energy	-0.04	0.02	0.03	-0.03	**-0.86**	-0.11
Experience fatigue	0.02	0.04	0.12	0.01	**-0.82**	-0.02
Rest	0.02	0.05	-0.03	0.06	**-0.80**	0.10
Fatigue suddenly	0.30	0.12	-0.11	0.11	-0.58	0.12
Look forward to	-0.02	0.03	-0.02	0.06	-0.06	**-0.86**
Cheer me up	0.04	0.06	0.04	-0.01	-0.09	**-0.80**
Unhappy	0.15	0.03	0.02	0.04	-0.04	**-0.76**
Depressed	0.15	0.03	0.07	0.08	0.00	**-0.76**

Note. Oblique rotation 0.65 cut-off

Table 12. Pattern matrix (factor loadings) for the function domain

Function Domain Item	Factor 1 "Cognitive Function"	Factor 2 "Social Relationships"	Factor 3 "Sleep"	Factor 4 "Sexual Function"	Factor 5 "Work Function"
Total Percent Variance, 71.47%					
Fog	**0.92**	0.02	-0.01	0.03	-0.02
Concentrating	**0.91**	-0.07	-0.01	0.04	-0.01
Mental quality of my life	**0.88**	0.03	-0.00	0.02	0.07
Shifting back and forth	**0.86**	0.01	0.00	-0.01	0.08
Thinking slow	**0.86**	0.05	-0.06	-0.02	0.05
Trouble finding words	**0.79**	0.04	-0.08	0.08	-0.06
Helpful advice	0.11	**0.89**	0.06	0.03	0.02
Someone will listen	0.06	**0.89**	-0.05	0.04	0.06
Someone understands	0.08	**0.87**	-0.05	0.04	0.06
Someone to help	0.03	**0.84**	0.03	-0.02	-0.04
Feel isolated	0.18	-0.62	0.07	0.04	0.20
Avoid talking to me	0.04	-0.54	-0.5	0.14	0.02
Scars sex	0.20	-0.40	0.04	-0.13	-0.03
Problems sleep	-0.01	0.01	**-0.93**	0.02	0.04
Sleep restless	-0.04	0.07	**-0.91**	0.03	0.02
Sleep quality	-0.06	0.06	**-0.90**	-0.06	0.09
Satisfied sleep	-0.03	0.01	**0.88**	0.05	0.05
Falling asleep	0.11	-0.11	-0.63	-0.02	-0.14
Tired	0.16	-0.13	-0.54	0.07	0.13
Interested sexual activity	-0.01	-0.05	0.01	**0.91**	-0.05
Sex	-0.05	-0.01	0.00	**0.91**	0.08
Satisfied sex	0.05	0.09	0.03	0.63	-0.13
Physical demands work	-0.03	0.02	-0.06	-0.09	**0.94**
Work ability	-0.02	0.05	0.01	0.04	**-0.89**
Mental demands work	0.32	-0.11	0.01	0.01	0.63

Note. Oblique rotation 0.65 cut-off

Table 13. Pattern matrix (factor loadings) for the health behaviors domain

Health Behavior Domain	Factor 1 "Diet"	Factor 2 " Exercise"	Factor 3 Unnamed
Total Percent Variance, 57.81%			
Bacon or sausage	**0.81**	0.11	0.01
French fries	**0.75**	-0.05	-0.02
Hot dogs	**0.70**	0.00	-0.14
Potato chips	0.63	-0.16	0.18
Work physical activity	-0.03	**0.82**	-0.21
Home physical activity	-0.12	**0.75**	0.29
Peanuts	0.12	0.08	**0.71**
Leisure physical activity	-0.03	0.53	0.57
Salad dressing	0.29	0.27	-0.52

Note. Oblique rotation 0.65 cut-off

Table 14. Pattern matrix (factor loadings) for the health services domain

Health Services Domain	Factor 1 "Patient-Provider Communica-tion"	Factor 2 "Health Information"	Factor 3 "Healthcare Competence"	Factor 4 "Economic Demands"
Total Percent Variance, 71.78%				
Doctor answer questions	**-0.86**	-0.04	0.07	-0.09
Health concern seriously	**-0.86**	-0.04	-0.08	-0.04
Ask doctor questions	**-0.85**	0.10	0.02	0.00
Explain health concern	**-0.83**	0.02	-0.08	0.09
Get doctor to do something	**-0.83**	-0.02	-0.11	-0.03
Ask doctor for more information	**-0.80**	-0.09	0.08	0.03
Written information	-0.04	**0.92**	0.03	-0.06
Explanation tests	0.01	**0.90**	0.03	-0.04
Informed treatments	0.06	**0.89**	-0.02	-0.05
Informed test results	-0.06	**0.88**	-0.02	0.02
Informed things to help yourself	0.04	**0.80**	0.07	0.03
Information internet	0.03	**0.74**	-0.06	0.12
Change healthcare ineffective	-0.12	0.05	**0.90**	-0.03
My plans for my health	-0.09	0.01	**0.86**	0.07
Goals health	-0.09	0.07	**-0.81**	0.05
Health doesn't turn out	0.00	0.01	**0.81**	0.10
Projects improve health	-0.10	-0.01	**-0.78**	0.10
Effective solutions to health problems	0.12	0.04	**0.72**	0.11
Money problems	0.03	-0.02	-0.00	**0.93**
Cost of cancer	0.02	0.00	-0.06	**0.90**
Loss of income	0.05	-0.05	0.08	**0.79**
Insurance	-0.07	0.09	0.02	**0.68**

Note. Oblique rotation 0.65 cut-off

Table 15. Parallel analysis to determine factor retention

Symptom Burden		
Raw Data	Threshold*	Interpretation
12.84	1.82	Retain
3.60	1.70	Retain
2.51	1.61	Retain
1.86	1.55	Retain
1.75	1.48	Retain
1.08	1.42	Not meaningful
Function		
Raw Data	Threshold*	Interpretation
8.68	1.71	Retain
3.31	1.58	Retain
2.68	1.50	Retain
1.90	1.43	Retain
1.30	1.37	Not meaningful
Health Behaviors		
Raw Data	Threshold*	Interpretation
2.51	1.38	Retain
1.64	1.26	Retain
1.05	1.17	Not meaningful
Health Services		
Raw Data	Threshold*	Interpretation
6.99	1.66	Retain
3.90	1.54	Retain
2.82	1.44	Retain
2.08	1.38	Retain

*95^{th} % of eigenvalues from parallel analysis

Table 16. Pattern matrix for the symptom burden domain: 5 fixed factors

Symptom Burden Domain Item	Factor 1 "Anxiety" and "depressive symptoms"	Factor 2 "Pain"	Factor 3 "Fear of recurrence"	Factor 4 "Body image"	Factor 5 "Fatigue"
Worries	**0.82**	-0.04	-0.03	0.00	-0.09
Unhappy	**0.82**	0.06	-0.02	0.09	0.05
Depressed	**0.82**	0.06	0.03	0.13	0.09
Fearful	**0.81**	0.02	0.14	-0.09	0.12
Emotional	**0.77**	-0.02	-0.02	-0.05	-0.07
Cheer me up	**0.76**	0.10	-0.01	0.05	0.01
Look forward to	**0.76**	0.08	-0.08	0.13	0.05
Tearful	**0.73**	0.00	0.03	-0.09	-0.08
Anxious	**0.71**	-0.10	0.17	-0.13	-0.09
Tense	**0.69**	-0.03	0.06	0.06	-0.10
Irritable	**0.66**	-0.05	-0.09	0.08	-0.15
Severe	0.00	**0.92**	-0.04	-0.01	0.01
Interfere	-0.03	**0.90**	0.03	0.05	0.01
Joint	-0.01	**0.83**	0.10	-0.11	0.01
Daily activities	-0.01	**0.81**	-0.02	0.05	-0.15
Burning	0.05	**0.79**	-0.07	0.06	-0.03
Cancer unsure	0.05	0.07	**0.84**	0.00	0.00
Cancer health	-0.09	0.05	**0.83**	-0.01	-0.08
Coming back	-0.04	-0.11	**0.82**	0.04	-0.08
Worry future	0.10	0.08	**0.81**	0.04	0.01
Worry health	0.05	0.05	**0.78**	0.09	-0.03
New symptoms	0.03	-0.07	**0.75**	0.05	0.07
I felt worried	0.41	0.15	0.44	-0.10	-0.14
Cover body	-0.04	-0.04	0.03	**0.87**	-0.06
Disfigured	0.06	0.00	0.03	**0.85**	0.01
Body looks	0.06	0.06	0.13	**0.80**	-0.02
Fatigued	0.04	0.00	0.04	-0.04	**-0.90**
Run-down	0.04	-0.02	0.05	0.01	**-0.86**
Energy	0.04	0.03	0.02	-0.02	**-0.85**
Rest	0.01	0.05	0.12	0.02	**-0.83**
Suddenly	-0.09	0.04	-0.02	0.05	**-0.83**

Note. Oblique rotation 0.65 cut-off

Table 17. Pattern matrix for the function domain: 4 fixed factors

Function Domain Item	Factor 1 "Cognitive function" and "Work"	Factor 2 "Social relationships"	Factor 3 "Sleep"	Factor 4 "Sexual function"
Fog	**0.89**	0.09	-0.05	0.01
Mental quality of life	**0.89**	0.05	-0.04	0.00
Shifting back and forth	**0.88**	0.03	-0.03	-0.03
Concentrating	**0.88**	-0.01	-0.05	0.02
Thinking slow	**0.87**	0.08	-0.09	-0.04
Trouble finding words	**0.74**	-0.12	-0.11	-0.10
Mental demands work	0.62	-0.36	0.04	0.03
Work ability	-0.46	0.43	-0.05	0.01
Physical demands work	0.44	-0.38	0.01	-0.06
Helpful advice	0.16	**0.87**	0.08	0.06
Someone will listen	0.13	**0.84**	-0.02	0.07
Someone to help	0.05	**0.84**	0.05	0.01
Someone understands	0.15	**0.83**	0.11	0.05
Feel isolated	0.24	**-0.68**	0.06	0.03
Avoid talking to me	0.12	-0.62	-0.06	-0.13
Scars sex	0.16	-0.37	-0.01	-0.15
Problem sleep	0.01	-0.01	**-0.93**	0.02
Sleep restless	-0.03	0.05	**-0.91**	0.04
Sleep quality	-0.02	0.02	**-0.89**	-0.05
Satisfied sleep	0.00	-0.02	**0.89**	0.05
Falling asleep	0.30	-0.05	**-0.65**	-0.03
Tired	0.21	-0.18	-0.54	0.07
Interested sexual activity	-0.03	-0.05	0.01	**0.92**
Sex	0.00	-0.07	0.01	**0.92**
Satisfied sex	-0.01	0.13	0.02	0.64

Note. Oblique rotation 0.65 cut-off

Table 18. Correlations among sub-scales on the symptom burden domain

	Anxiety	Pain	Fear of recurrence	Body image	Fatigue	Depressive symptoms
Anxiety	1	0.29**	0.50**	0.33**	0.50**	0.70**
Pain	0.29**	1	0.20**	0.29**	0.51**	0.35**
Fear of recurrence	0.50**	0.20**	1	0.34**	0.43**	0.44**
Body image	0.33**	0.29**	0.35**	1	0.35**	0.38**
Fatigue	0.50**	0.51**	0.43**	0.35**	1	0.49**
Depressive symptoms	0.70**	0.35**	0.44**	0.38**	0.49**	1

**Correlation significant at the 0.01 level (2-tailed).

Table 19. Correlations among sub-scales on the function domain

	Cognitive function	Social relationships	Sleep	Sexual function	Work
Cognitive function	1	0.20**	0.40**	0.16*	0.45**
Social relationships	0.20**	1	0.20*	0.18*	0.37*
Sleep	0.40**	0.20*	1	0.19**	0.26**
Sexual function	0.16*	0.18**	0.19**	1	0.15**
Work	0.45**	0.37**	0.26**	0.15*	1

*0.05 **0.01

Table 20. Correlations among sub-scales on the health behavior domain

	Cigarette user	Alcohol	Diet	Exercise
Cigarette user	1	-0.13*	-0.11	0.01
Alcohol	-0.13*	1	0.17**	0.00
Diet	-0.11	0.17**	1	0.12
Exercise	0.01	0.01	0.12	1

*0.05 **0.01

Table 21. Correlations among sub-scales on the health services domain

	Health information	Health competence	Economic demands	Communication
Health information	1	0.22**	0.34**	0.20**
Health competence	0.22**	1	0.27**	0.37**
Economic	0.34**	0.27**	1	0.14*
Communication	0.20**	0.37*	0.14*	1

*0.05 **0.01

Table 22. Multi-item-multi-trait scaling tests of CSPro and gold standard measures: Divergent validity estimates

CSPro Construct/Item	Gold-standard measure/Estimate		
	Behavioral Risk Factor Surveillance System		
Fear of recurrence	**Physical activity**	**Moderate activity**	**Vigorous activity**
Cancer health	0.01	0.04	0.06
Worry future	0.08	0.05	0.112
Cancer unsure	0.02	0.05	0.07
Coming back	0.12	-0.003	0.15*
Worry health	0.04	0.06	0.04
	Modified Version of the Patients' Perceived Involvement in Care Scale		
Cognitive Function	**Healthcare provider information**	**Patient information**	**Healthcare provider facilitation**
Thinking slow	-0.10	0.01	0.12
Shifting back and forth	-0.10	0.05	0.07
Mental quality of life	-0.13*	-0.01	0.03
Concentrating	-0.14*	-0.02	0.07
Fog	-0.12	-0.05	0.05
Trouble finding words	-0.08	0.08	0.17**
	Center for Epidemiologic Studies Depression Scale		
Diet	**Total score**		
Bacon or sausage	0.04	———	———
Hot dogs	0.08	———	———
French fries	0.07	———	———
	Pittsburgh Sleep Quality Index		
Health information	**Total score**		
Written information	0.04	———	———
Explanation tests	0.08	———	———
Informed treatments	0.05	———	———
Informed test results	0.08	———	———
Informed things to help yourself	0.10	———	———
Information internet	0.11	———	———

*0.05 **0.01

Note. Dash indicates no additional sub-scale.

Table 23. Multi-item-multi-trait scaling tests of CSPro and gold standard measures: Convergent validity estimates

CSPro Construct/Item	Gold-standard measure/Estimate		
	Center for Epidemiologic Studies Depression Scale		
Depressive symptoms	**Total score**		
Look forward to	0.73**	_____	_____
Cheer me up	0.75**	_____	_____
Unhappy	0.76**	_____	_____
Depressed	0.77**	_____	_____
	Pittsburgh Sleep Quality Index		
	Total score		
Sleep		_____	_____
Problem sleep	0.70*	_____	_____
Sleep restless	0.59**	_____	_____
Sleep quality	0.67**	_____	_____
Satisfied sleep	-0.68**[a]	_____	_____
	Behavioral Risk Factor Surveillance System		
Exercise	**Physical activity**	**Moderate activity**	**Vigorous activity**
Work physical activity	-0.003	0.12	-0.09
Home physical activity	0.08	0.07	0.12
	Modified Version of the Patients' Perceived Involvement in Care Scale		
Patient-provider communication	**Healthcare provider information**	**Patient information[a]**	**Healthcare provider facilitation[a]**
Ask doctor questions	0.36**	-0.38*	-0.39**
Doctor answer questions	0.49**	-0.35**	-0.48**
Explain health concern	0.35**	-0.41**	-0.43**
Health concern seriously	0.45**	-0.35**	-0.53**
Get doctor to do something	0.52**	-0.33**	-0.52**
Ask doctor for more information	0.43**	-0.40**	-0.40**

*0.05 **0.01

Note. [a]In expected direction. Dash indicates no additional sub-scale.

Table 24. Test-retest reliability of the CSPro

Domain/Sub-scale	Pre/post Correlation Coefficient
Symptom Burden	
Anxiety	0.80**
Pain	0.74**
Fear of recurrence	0.78**
Body image	0.78**
Fatigue	0.62**
Depressive symptoms	0.81**
Health Behaviors	
Diet	0.69**
Exercise	0.57**
Alcohol	0.49**
Cigarette smoking	0.94**
Function	
Cognitive function	0.81**
Social relations	0.81**
Sleep	0.77**
Sexual function	0.80**
Work	0.88**
Health Services	
Patient-provider communication	0.79**
Health competence	0.64**
Health information	0.48**
Economic demands	0.89**

**0.01

Note. 14 -39 days between first and second CSPro completion (Mdn = 17.0)

Table 25. Univariate correlations between potential confounders and CSPro sub-scales

***Domain*/Construct**	**Correlations**		
	Social desirability	**Age**	**Time since completion of treatment**
Symptom Burden			
Anxiety	-0.28**	-0.23**	-0.17**
Pain	-0.11	0.22**	0.04
Fear of recurrence	-0.12*	-0.08	-0.14*
Fatigue	-0.11	-0.09	-0.04
Body image	-0.09	-0.10	-0.02
Depressive symptoms	-0.20**	-0.13	-0.05
Function			
Cognitive function	-0.19**	-0.04	-0.14*
Sexual function	-0.07	0.15*	-0.01
Social relations	-0.07	-0.10	0.23**
Sleep	-0.08	0.07	0.07
Work	-0.07	0.05	-0.04
Health Behaviors			
Exercise	0.08	0.12	0.01
Diet	-0.05	-0.29**	-0.03
Health Service Needs			
Patient-provider Communication	0.09	0.24**	-0.03
Health information	-0.04	-0.14	-0.19*
Health competence	-0.16*	0.01	0.04
Economic demands	-0.02	-0.10	-0.09

*0.05 **0.01

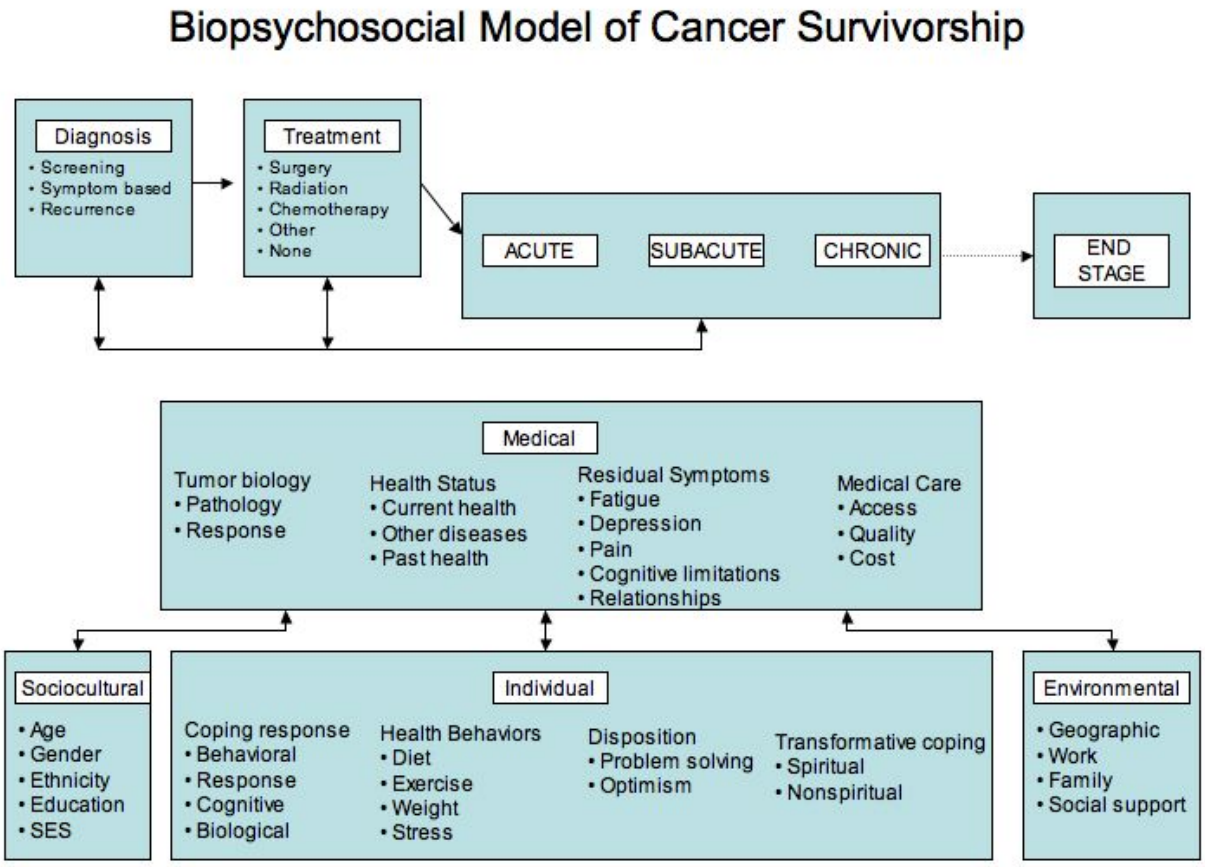

Figure 1. Biopsychosocial Model of Cancer Survivorship (140)

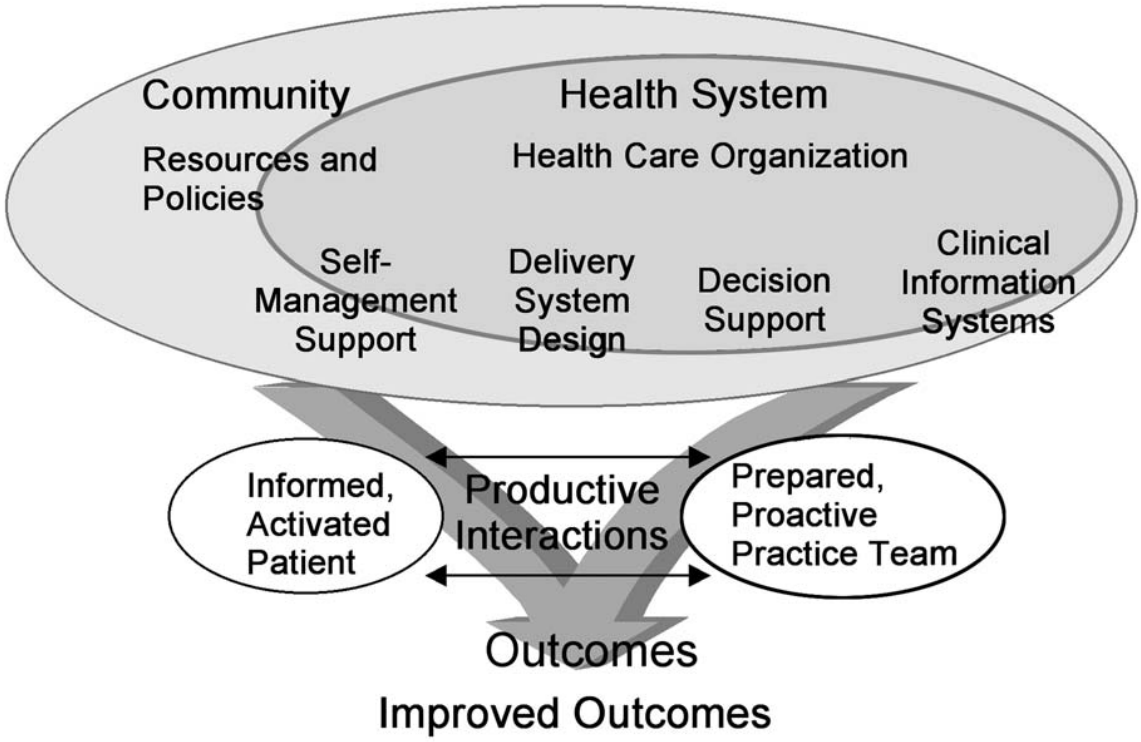

Figure 2. Chronic Care Model (379)

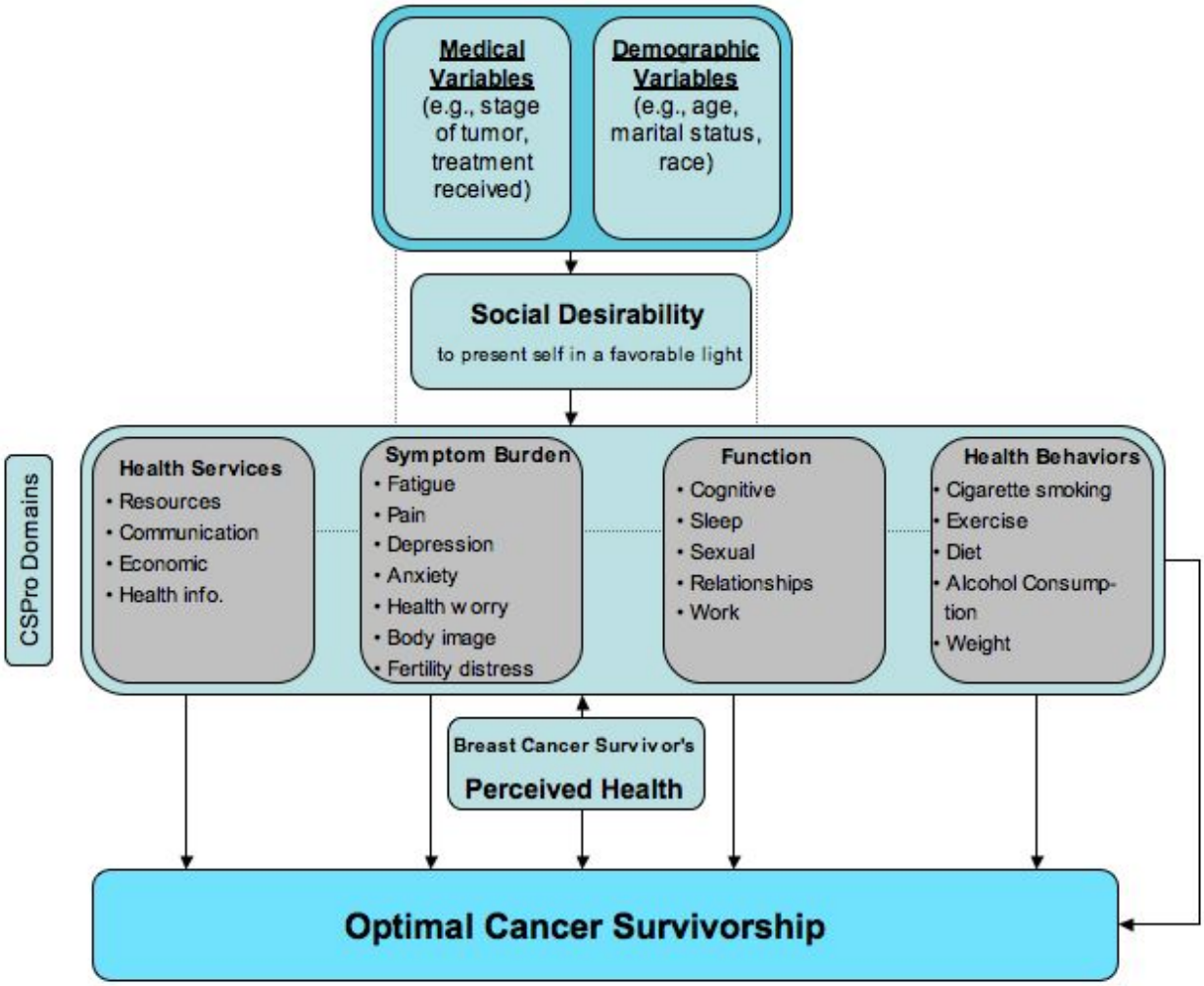

Figure 3. Study model
Note. Dotted lines indicate inconsistent relationship between constructs.

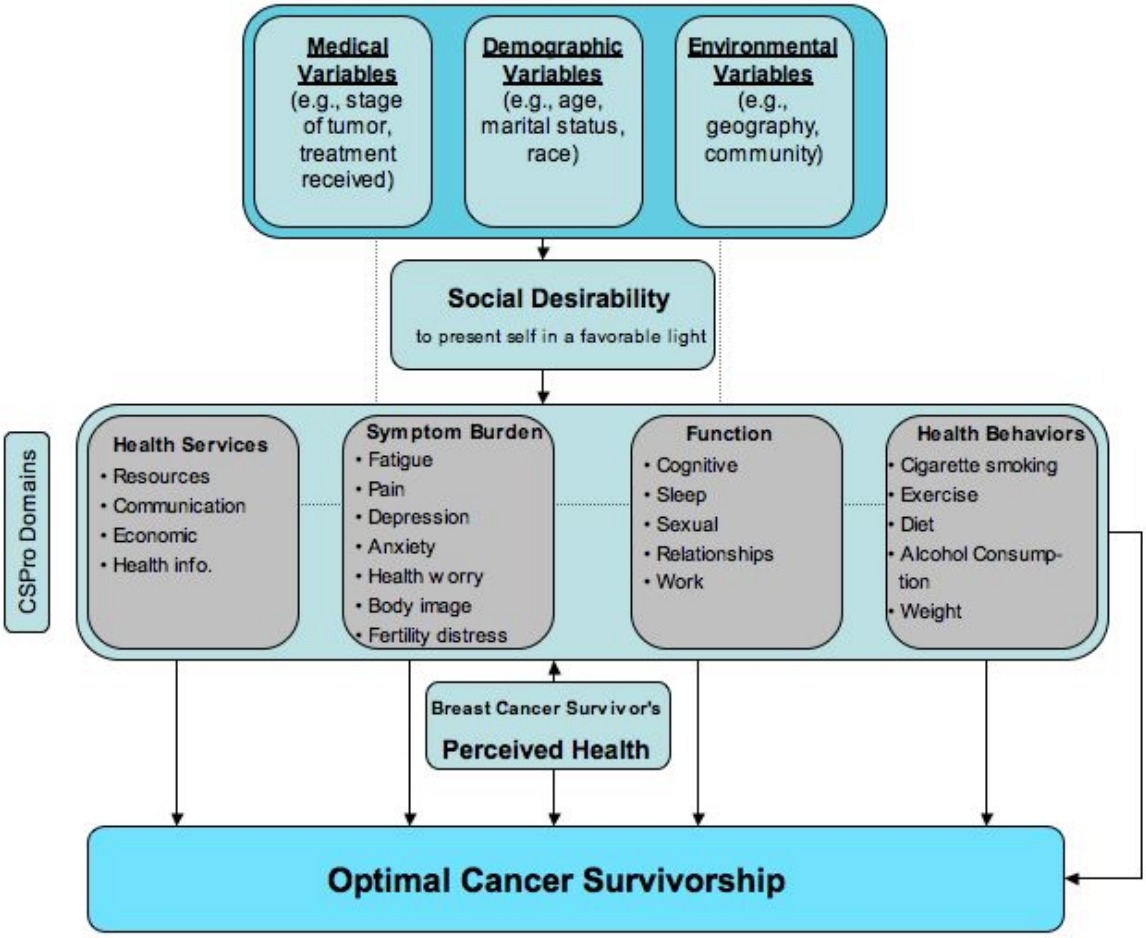

Figure 4. Comprehensive study model
Note. Dotted lines indicate inconsistent relationship between constructs.

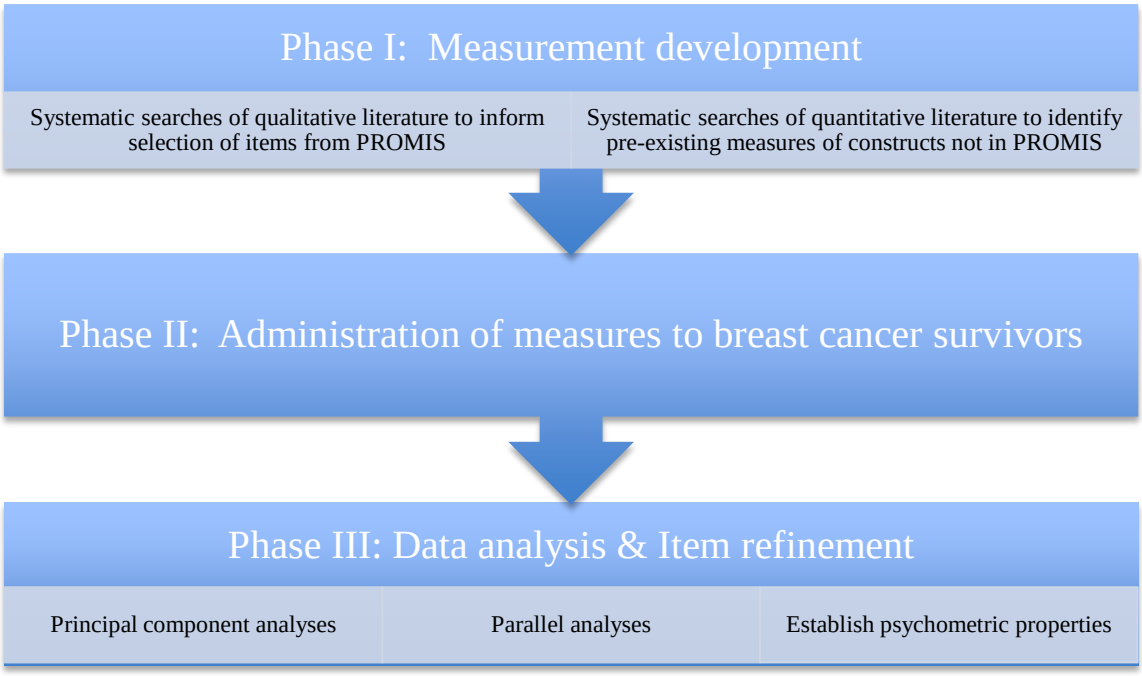

Figure 5. Phases of study

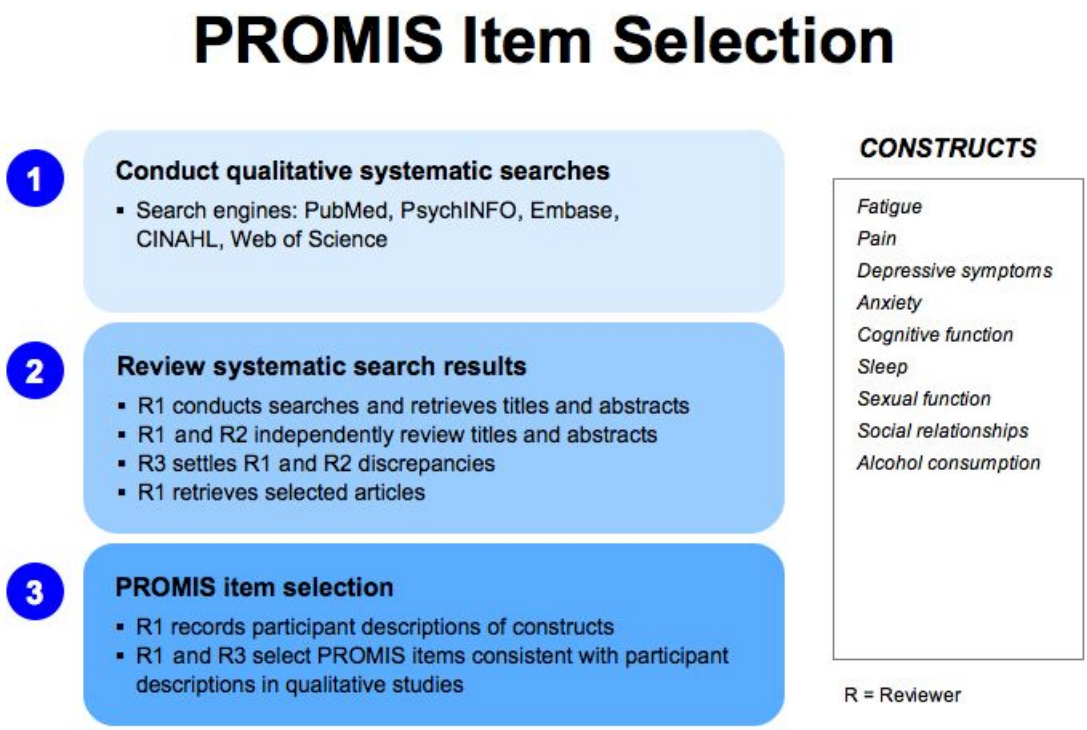

Figure 6. Systematic process to select items from PROMIS

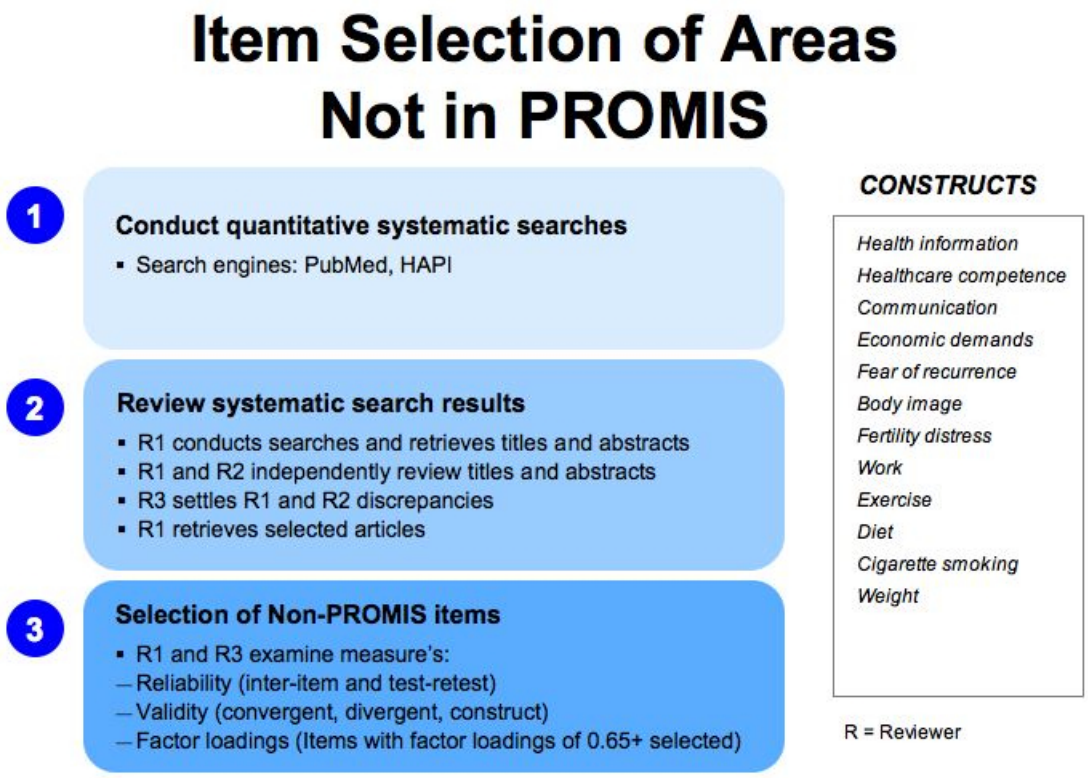

Figure 7. Systematic process to select items not from PROMIS

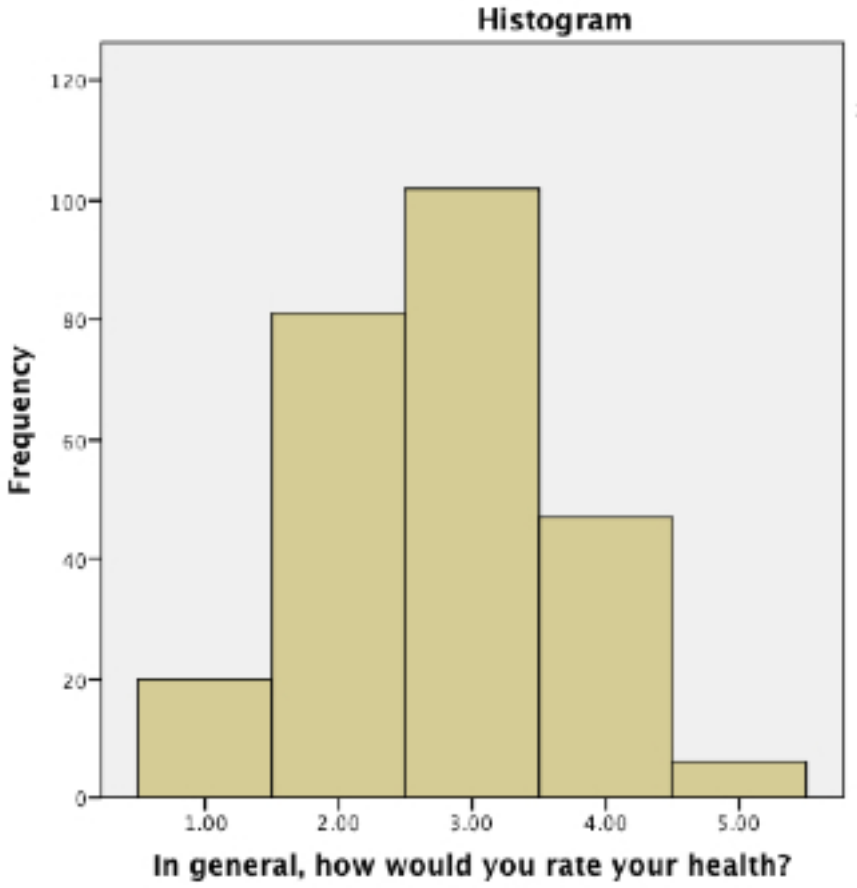

Figure 8. Self-rated general health distribution.

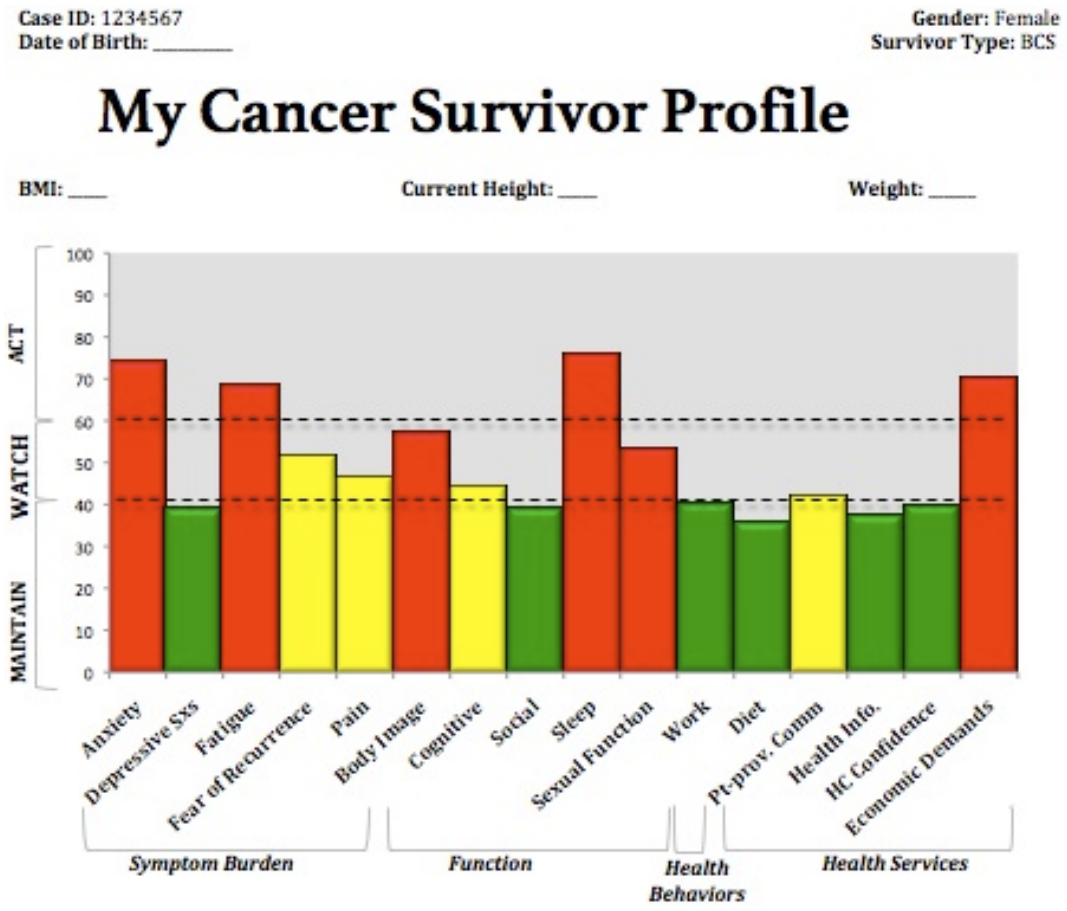

Figure 9. Sample participant Cancer Survivor Profile with standardized scores

Appendix A: Institutional Review Board approval letter and flyers

A study for
Breast Cancer Survivors

A study to develop a questionnaire to help breast cancer survivors and providers identify and improve problems experienced after cancer.

To participate, individuals need to be:

1. Female breast cancer survivor (stages I-III)
2. Completed treatment (radiation, chemotherapy, and/or surgery) between 1 day and 5 years ago
3. Age 21 or older
4. Have access to the Internet

We will ask you to take a short online questionnaire of symptoms, function, health behaviors, and health service needs that will require about 45 minutes of your time. This study can be taken from any computer with Internet access. Compensation will be provided for your participation. We may invite you to answer some additional questions 2-weeks later. This will take about 15 minutes of your time.

To see if you are eligible for our study, please go to:

https://www.surveymonkey.com/s/BCSurvivorStudy44

For more information, email CancerSurvivor-ggg@usuhs.edu or call (301) 295-9659.

This research is being run by the Uniformed Services University of Health Sciences in Bethesda, MD.

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Breast Cancer Survivors

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To see if you are eligible for our study, please go to:

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For more information, email CancerSurvivor-ggg@usuhs.edu or call (301) 295-9659.

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Appendix B: Recruitment sources

Site	Location
Alaska Cancer Care Alliance	Alaska
American Cancer Society	National
American Cancer Society, Maryland State Lead Ambassador	Maryland
Breast Cancer Awareness- Cumberland Valley	Regional
Breast Cancer Mailing List	National
Breast Cancer Partner	National
Breast Cancer Recovery	National
Breast Cancer Society	National
Calvert Memorial Hospital	Regional
Cancer Connections Miami, FL	Regional
Cancer Research Study Board	National
Catch for Recovery	National
Delaware Cancer Coalition	Delaware
District of Columbia Nurse Navigators	Regional
Healing Well	National
Hope Connections Bethesda, MD	Regional
Hope for Young Adults with Cancer	National
Living Beyond Cancer	National
Making Strides Against Breast Cancer- Las Vegas	Regional
Pink Link	National
Roswell Park Cancer Institute	New York
Sibley Hospital	Regional
Sisters Network New Jersey	New Jersey
Spring Publishing Company	National
Strength & Courage	National
Suburban Hospital	Regional
Ulman Cancer Fund for Young Adults	National
Young Breast Cancer Survivorship Program UCLA-LIVESTRONG Survivorship Center of Excellence	California
Young Survival Coalition National	National

Appendix C: Study measures

Demographic/medical questions

What is your date of birth?

_____

What is your highest level of education?

1. Less than high school
2. High school
3. Some college
4. Associate's degree
5. Bachelor's degree
6. Some graduate school
7. Graduate degree

What is your marital status?

1. Single
2. Single, cohabitating
3. Married
4. Divorced
5. Widowed

What is your ethnicity?

1. Non-Hispanic or Non-Latino
2. Hispanic or Latino

What is your race?

1. American Indian/Alaska Native
2. Asian
3. Native Hawaiian or Other Pacific Islander
4. Black or African American
5. Caucasian
6. Other

What is your employment status?

1. Unemployed (by choice)
2. Unemployed (not by choice)
3. Works full-time
4. Works part-time

If you work, what is your job title?

_____

What is your estimated household income?

1. Less than $10,000
2. $10,000 - $19,000
3. $20,000 - $39,000

4. $40,000 - $59,000
5. $60,000 - $79,000
6. $80,000 - $99,000
7. $100,000 or more

Where was your breast tumor located?
1. Right breast
2. Left breast
3. Both breasts
4. Unsure

What stage of breast cancer were you diagnosed with?
1. Stage I
2. Stage II
3. Stage III

Were you treated with chemotherapy for breast cancer?
1. Yes
2. No

If you were treated with chemotherapy for breast cancer, what type/regimen did you receive?

_____

If you were treated with chemotherapy for breast cancer, how many cycles did you receive?

_____

Were you treated with radiation for breast cancer?
1. Yes
2. No

Were you treated with surgery for breast cancer?
1. Yes
2. No

If you were treated with surgery for breast cancer, what type of surgery did you have?
1. Lumpectomy
2. Mastectomy

Did you receive any adjuvant treatment for breast cancer?
1. Yes
2. No

If you received adjuvant treatment for breast cancer, what adjuvant treatment did you receive? Please indicate if you are currently on adjuvant treatment?
Name _____ Currently taking: Yes or No

Name _____ Currently taking: Yes or No

Name _____ Currently taking: Yes or No

Name _____ Currently taking: Yes or No

Name _____ Currently taking: Yes or No

Did you receive other treatment for breast cancer?
1. Yes
2. No

If you received other treatment for breast cancer, please specify?
Name _____ Currently taking: Yes or No

Name _____ Currently taking: Yes or No

Name _____ Currently taking: Yes or No

Name _____ Currently taking: Yes or No

Name _____ Currently taking: Yes or No

What was the date you were diagnosed with breast cancer?
Month: _____
Day: _____
Year: _____

What was the date that all primary treatment (radiation, chemotherapy, surgery) was completed?
Month: _____
Day: _____
Year: _____

What is your menopausal status?
1. Pre-menopausal prior to cancer, post-menopausal after treatment
2. Pre-menopausal prior to treatment, pre-menopausal after treatment
3. Post-menopausal before diagnosis or treatment

Please list any other medications you are on?
Name _____ Dosage _____

Name _____ Dosage _____

Name _____ Dosage _____

Name _____ Dosage _____

Name _____ Dosage _____

Name _____ Dosage _____

Preliminary Cancer Survivor Profile

Given your life as it is now, how do you feel about having had cancer?
Mark the box that best describes how much you agree or disagree with each statement.

1. Having had cancer makes me feel uncertain about my health.
    1 = Strongly disagree
    2 = Disagree
    3 = Neutral
    4 = Agree
    5 = Strongly agree
2. I worry about the future.
    1 = Strongly disagree
    2 = Disagree
    3 = Neutral
    4 = Agree
    5 = Strongly agree
3. Having had cancer makes me feel unsure about the future.
    1 = Strongly disagree
    2 = Disagree
    3 = Neutral
    4 = Agree
    5 = Strongly agree
4. I worry about cancer coming back.
    1 = Strongly disagree
    2 = Disagree
    3 = Neutral
    4 = Agree
    5 = Strongly agree
5. New symptoms make me worry about the cancer coming back.
    1 = Strongly disagree
    2 = Disagree
    3 = Neutral
    4 = Agree
    5 = Strongly agree
6. I worry about my health.
    1 = Strongly disagree
    2 = Disagree
    3 = Neutral
    4 = Agree
    5 = Strongly agree
7. I feel disfigured.
    1 = Strongly disagree
    2 = Disagree

3 = Neutral
4 = Agree
5 = Strongly agree

8. I sometimes wear clothing to cover parts of my body.
   1 = Strongly disagree
   2 = Disagree
   3 = Neutral
   4 = Agree
   5 = Strongly agree
9. I worry about how my body looks.
   1 = Strongly disagree
   2 = Disagree
   3 = Neutral
   4 = Agree
   5 = Strongly agree

The following questions are about having a family.
Mark the box whether you agree or disagree with each statement.

10. Before being diagnosed with cancer, had you wanted to have a child (or another child)?
    1 = Yes
    2 = No
11. Since having had cancer, have you wanted to have a child (or another child)?
    1= Yes
    2= No
12. When I see families with children I feel left out.
    1 = Strongly disagree
    2 = Disagree
    3 = Neutral
    4 = Agree
    5 = Strongly agree
13. I can't help comparing myself with friends who have children.
    1 = Strongly disagree
    2 = Disagree
    3 = Neutral
    4 = Agree
    5 = Strongly agree
14. I will do just about anything to have a child (or another child).
    1 = Strongly disagree
    2 = Disagree
    3 = Neutral
    4 = Agree
    5 = Strongly agree
15. Having a child (or another child) is not necessary for my happiness.
    1 = Strongly disagree

2 = Disagree
3 = Neutral
4 = Agree
5 = Strongly agree

16. I could visualize a happy life together, without a child (or another child).
    1 = Strongly disagree
    2 = Disagree
    3 = Neutral
    4 = Agree
    5 = Strongly agree
    6 = Not applicable
17. We could have a long, happy relationship without a child (or another child).
    1 = Strongly disagree
    2 = Disagree
    3 = Neutral
    4 = Agree
    5 = Strongly agree
    6 = Not applicable

The next set of questions relate to how you view your health.
Mark the box that best describes how much you agree or disagree with the statement.

18. No matter how hard I try, my health just doesn't turn out the way I would like.
    1 = Strongly disagree
    2 = Disagree
    3 = Neutral
    4 = Agree
    5 = Strongly agree
19. It is difficult for me to find effective solutions to the health problems that come my way.
    1 = Strongly disagree
    2 = Disagree
    3 = Neutral
    4 = Agree
    5 = Strongly agree
20. I succeed in the projects I undertake to improve my health.
    1 = Strongly disagree
    2 = Disagree
    3 = Neutral
    4 = Agree
    5 = Strongly agree
21. I'm generally able to accomplish my goals with respect to my health.
    1 = Strongly disagree
    2 = Disagree
    3 = Neutral

4 = Agree
5 = Strongly agree

22. I find my efforts to change things I don't like about my health are ineffective.
    1 = Strongly disagree
    2 = Disagree
    3 = Neutral
    4 = Agree
    5 = Strongly agree
23. Typically, my plans for my health don't work out well.
    1 = Strongly disagree
    2 = Disagree
    3 = Neutral
    4 = Agree
    5 = Strongly agree

The next set of questions ask about how confident you are in your ability to interact with your doctor.
Mark the box about how confident you are in your ability:

24. How confident are you in your ability to ask a doctor questions about your chief health concern?
    1 = Not at all
    2 = A little bit
    3 = Somewhat
    4 = Quite a bit
    5 = Very much
25. How confident are you in your ability to get a doctor to answer all your questions?
    1 = Not at all
    2 = A little bit
    3 = Somewhat
    4 = Quite a bit
    5 = Very much
26. How confident are you in your ability to explain your chief health concern to a doctor?
    1 = Not at all
    2 = A little bit
    3 = Somewhat
    4 = Quite a bit
    5 = Very much
27. How confident are you in your ability to get a doctor to take your chief health concern seriously?
    1 = Not at all
    2 = A little bit
    3 = Somewhat
    4 = Quite a bit

5 = Very much

28. How confident are you in your ability to get a doctor to do something about your chief health concern?
    1 = Not at all
    2 = A little bit
    3 = Somewhat
    4 = Quite a bit
    5 = Very much
29. How confident are you in your ability to ask a doctor for more information if you don't understand what he or she said?
    1 = Not at all
    2 = A little bit
    3 = Somewhat
    4 = Quite a bit
    5 = Very much

The next set of questions is about your relationship with others since the end of primary treatment (e.g., chemotherapy, radiation, surgery).
Mark the box that best describes how you feel about each statement.

30. I feel people avoid talking to me.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Usually
    5 = Always
31. I feel isolated from others.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Usually
    5 = Always
32. I have someone who will listen to me when I need to talk.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Usually
    5 = Always
33. I have someone who understands my problems.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Usually
    5 = Always
34. I can get helpful advice from others when dealing with a problem.

1 = Never
2 = Rarely
3 = Sometimes
4 = Often
5 = Always

35. Is someone available to help you if you need it?
1 = Never
2 = Rarely
3 = Sometimes
4 = Usually
5 = Always

The following questions ask about your ability to perform at work.
Mark the box that best describes how you feel about each statement.

36. Are you currently employed?
1 = Yes
2 = No

37. Current work ability compared to your highest work ability ever:
How many points would you give your current work ability?
0 means that you cannot currently work and 5 is your work ability at its best.

0	1	2	3	4	5
completely unable to work					work ability at its best

38. Work ability in its relation to the demands of the job.
How do you rate your current work ability with respect to the **physical** demands of your work?
1 = Very good
2 = Rather good
3 = Moderate
4 = Rather poor
5 = Very poor

39. Work ability in its relation to the demands of the job.
How do you rate your current work ability with respect to the **mental** demands of your work?
1 = Very good
2 = Rather good
3 = Moderate
4 = Rather poor
5 = Very poor

The next set of questions is about challenges you may have had in the past **7 days**.
Mark the box that best describes how you feel about each statement.

*In the past **7 days***

40. How much did pain interfere with your day-to-day activities?
    1 = Not at all
    2 = A little bit
    3 = Somewhat
    4 = Quite a bit
    5 = Very much
41. How severe was your pain?
    1 = Not at all
    2 = A little bit
    3 = Somewhat
    4 = Quite a bit
    5 = Very much
42. How severe was your joint pain?
    1 = Not at all
    2 = A little bit
    3 = Somewhat
    4 = Quite a bit
    5 = Very much
43. How much did pain (e.g., back pain, arm pain, hand pain, hip pain, bone pain, muscle pain) affect your daily activities?
    1 = Not at all
    2 = A little bit
    3 = Somewhat
    4 = Quite a bit
    5 = Very much
44. How much did you experience burning and/or sharp pain?
    1 = Not at all
    2 = A little bit
    3 = Somewhat
    4 = Quite a bit
    5 = Very much

The next set of questions is about challenges you may have had in the past **7 days.**
Mark the box that best describes how you feel about each statement.
*In the past **7 days***

45. I was satisfied with my sleep.
    1 = Not at all
    2 = A little bit
    3 = Somewhat
    4 = Quite a bit
    5 = Very much
46. I had difficulty falling asleep.
    1 = Not at all

2 = A little bit
3 = Somewhat
4 = Quite a bit
5 = Very much

47. My sleep was restless.
    1 = Not at all
    2 = A little bit
    3 = Somewhat
    4 = Quite a bit
    5 = Very much
48. I had a problem with my sleep.
    1 = Not at all
    2 = A little bit
    3 = Somewhat
    4 = Quite a bit
    5 = Very much
49. I felt tired.
    1 = Not at all
    2 = A little bit
    3 = Somewhat
    4 = Quite a bit
    5 = Very much
50. My sleep quality was.
    1 = Very good
    2 = Good
    3 = Fair
    4 = Poor
    5 = Very poor

The next set of questions is about challenges you may have had in the past **7 days.**
Mark the box that best describes how you feel about each statement.
*In the past **7 days***

51. How run-down did you feel on average?
    1 = Not at all
    2 = A little bit
    3 = Somewhat
    4 = Quite a bit
    5 = Very much
52. How fatigued were you on average?
    1 = Not at all
    2 = A little bit
    3 = Somewhat
    4 = Quite a bit
    5 = Very much
53. To what degree did you feel that you had no energy?

1 = Not at all
2 = A little bit
3 = Somewhat
4 = Quite a bit
5 = Very much

54. How often did you need to rest during the day?
    1 = Not at all
    2 = A little bit
    3 = Somewhat
    4 = Quite a bit
    5 = Very much
55. How often did you experience fatigue?
    1 = Not at all
    2 = A little bit
    3 = Somewhat
    4 = Quite a bit
    5 = Very much
56. How often did your fatigue come on suddenly?
    1 = Not at all
    2 = A little bit
    3 = Somewhat
    4 = Quite a bit
    5 = Very much

The next set of questions is about challenges you may have had in the past **7 days.**
Mark the box that best describes how you feel about each statement.
*In the past **7 days***

57. I felt like nothing could cheer me up.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Often
    5 = Always
58. I felt unhappy.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Often
    5 = Always
59. I felt depressed.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Often
    5 = Always

60. I felt that I had nothing to look forward to.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Often
    5 = Always
61. I felt very emotional.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Often
    5 = Always
62. I felt tearful or like crying.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Often
    5 = Always

The next set of questions is about challenges you may have had in the past **7 days.**
Mark the box that best describes how you feel about each statement.
*In the past **7 days***

63. I felt anxious.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Often
    5 = Always
64. I felt fearful.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Often
    5 = Always
65. I felt tense.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Often
    5 = Always
66. My worries overwhelmed me.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Often

5 = Always

67. I felt irritable.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Often
    5 = Always
68. I felt worried about my health.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Often
    5 = Always

The next set of questions is about challenges you may have had in the past **7 days.**
Mark the box that best describes how you feel about each statement.
*In the past **7 days***

69. My thinking has been slow.
    1 = Never
    2 = Rarely (373)
    3 = Sometimes (Two or three times)
    4 = Often (About once a day)
    5 = Very often (Several times a day)
70. I have had trouble shifting back and forth between different activities that require thinking.
    1 = Never
    2 = Rarely (373)
    3 = Sometimes (Two or three times)
    4 = Often (About once a day)
    5 = Very often (Several times a day)
71. My problems with memory, concentration, or making mental mistakes have interfered with the quality of my life.
    1 = Never
    2 = Rarely (373)
    3 = Sometimes (Two or three times)
    4 = Often (About once a day)
    5 = Very often (Several times a day)
72. I have had trouble concentrating.
    1 = Never
    2 = Rarely (373)
    3 = Sometimes (Two or three times)
    4 = Often (About once a day)
    5 = Very often (Several times a day)
73. My brain was in a fog.
    1 = Never

2 = Rarely (373)
3 = Sometimes (Two or three times)
4 = Often (About once a day)
5 = Very often (Several times a day)

74. I have had trouble finding words when talking to someone.
    1 = Never
    2 = Rarely (373)
    3 = Sometimes (Two or three times)
    4 = Often (About once a day)
    5 = Very often (Several times a day)

The next set of questions is about challenges you may have had in the past **30 days.**
Mark the box that best describes how you feel about each statement.
*In the past **30 days***

75. How interested have you been in sexual activity?
    1 = Not at all
    2 = A little bit
    3 = Somewhat
    4 = Quite a bit
    5 = Very much
76. How often have you felt like you wanted to have sex?
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Often
    5 = Always
77. How satisfied have you been with your sex life?
    1 = Not at all
    2 = A little bit
    3 = Somewhat
    4 = Quite a bit
    5 = Very much
78. How much have scars from surgery affected your satisfaction with your sex life?
    1 = Not at all
    2 = A little bit
    3 = Somewhat
    4 = Quite a bit
    5 = Very much

The next set of questions are about financial matters related to cancer.
Indicate how often each of these statements has been true for you in the past **30 days.**

79. You had financial problems because of the cost of cancer surgery or treatment.
    1 = Never
    2 = Rarely

3 = Sometimes
4 = Often
5 = Always

80. You had problems with insurance because of cancer.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Often
    5 = Always
81. You had money problems that arose because you had cancer.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Often
    5 = Always
82. You had financial problems due to a loss of income as a result of cancer.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Often
    5 = Always

The next set of questions is about challenges you may have had in the past **30 days.**
Mark the box that best describes how you feel about each statement.
*In the past **30 days***

83. Did you drink any type of alcoholic beverage?
    1 = Yes
    2 = No (Skip to 87)
84. I took risks when I drank.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Often
    5 = Almost always
85. Drinking created problems between me and others.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Often
    5 = Almost always
86. I had trouble getting things done after I drank.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Often

5 = Almost always

Please think about what you usually ate or drank during the past month, that is, the past **30 days.** Please read each question and:
- Report how many times per day, week, or month you ate each food.

87. How many times per **day**, **week**, or **month** did you **usually** eat **bacon** or **sausage**, not including low fat, light, or turkey varieties?

1 = Never
2 = 1-3 times last month
3 = 1-2 times per week
4 = 3-4 times per week
5 = 5-6 times per week
6 = 1 time per day
7 = 2 times per day
8 = 3 times per day
9 = 4 or more times per day

88. How often did you eat **hot dogs** made of beef or pork?

1 = Never
2 = 1-3 times last month
3 = 1-2 times per week
4 = 3-4 times per week
5 = 5-6 times per week
6 = 1 time per day
7 = 2 times per day
8 = 3 times per day
9 = 4 or more times per day

89. How often did you use **regular fat salad dressing or mayonnaise**, including on salad and sandwiches? Do **not** include low-fat, light, or diet dressings.

1 = Never
2 = 1-3 times last month
3 = 1-2 times per week
4 = 3-4 times per week
5 = 5-6 times per week
6 = 1 time per day
7 = 2 times per day
8 = 3 times per day
9 = 4 or more times per day

90. How often did you eat **French fries, home fries,** or **hash brown potatoes**?

1 = Never
2 = 1-3 times last month
3 = 1-2 times per week
4 = 3-4 times per week
5 = 5-6 times per week
6 = 1 time per day
7 = 2 times per day

8 = 3 times per day
9 = 4 or more times per day

91. How often did you eat **peanuts, walnuts, seeds,** or **other nuts**? Do **not** include peanut butter.

1 = Never
2 = 1-3 times last month
3 = 1-2 times per week
4 = 3-4 times per week
5 = 5-6 times per week
6 = 1 time per day
7 = 2 times per day
8 = 3 times per day
9 = 4 or more times per day

92. How often did you eat **regular fat potato chips, tortilla chips, or corn chips**? Do **not** include low-fat chips.

1 = Never
2 = 1-3 times last month
3 = 1-2 times per week
4 = 3-4 times per week
5 = 5-6 times per week
6 = 1 time per day
7 = 2 times per day
8 = 3 times per day
9 = 4 or more times per day

Below are questions about needs that you may have experienced as a result of having cancer. Mark the box that best describes whether you have needed help with these needs in the last **30 days**. There are 5 possible answers to choose from:

No Need **1 Not applicable-** This was not a problem for me as a result of cancer.

2 Satisfied- I did need help with this, but my need for help was satisfied at the time.

Some Need **3 Low need-** This item caused me concern or discomfort. I had little need for additional help.

4 Moderate need- This item caused me concern or discomfort. I had some need for additional help.

5 High need- This item caused me concern or discomfort. I had a strong need for additional help.

93. Being given written information about important aspects of your care.

1 = Not applicable
2 = Satisfied
3 = Low need
4 = Moderate need
5 = High need

94. Being given explanations of those tests for which you would like explanations.

1 = Not applicable
2 = Satisfied
3 = Low need
4 = Moderate need
5 = High need

95. Being adequately informed about the benefits and side-effects of treatments before you choose to have them.

1 = Not applicable
2 = Satisfied
3 = Low need
4 = Moderate need
5 = High need

96. Being informed about your test results as soon as feasible.

1 = Not applicable
2 = Satisfied
3 = Low need
4 = Moderate need
5 = High need

97. Being informed about things you can do to help yourself get well.

1 = Not applicable
2 = Satisfied
3 = Low need
4 = Moderate need
5 = High need

98. Being able to judge the quality of cancer related information provided on the Internet.

1 = Not applicable
2 = Satisfied
3 = Low need
4 = Moderate need
5 = High need

For the next set of questions, use the following as a guide to describe your activity level:

1. **Physical Inactivity**: The inactive person spends most waking hours sitting or standing quietly. Activities include working at a desk, reading, watching television, or other quiet pursuits. Usually does not walk more than a few minutes.

2. **Light Physical Inactivity**: This person usually walks more than 10 minutes at a time each day, leisurely rides a bicycle, fishes, bowls, golfs, or engages in light carpentry, light gardening, light industrial work, teaching, or light housework on a regular basis.

3. **Moderate Physical Activity:** This person participates in such activities as brisk walking, recreation or doubles tennis, or swimming; or works in such occupations as mail carrier, telephone repair, light building, and construction; or engages in housework and home repairs or moderate gardening.

4. **Heavy Physical Activity:** This person performs vigorous activity on a regular basis, including jogging, singles tennis, paddleball, or high-intensity aerobics; or engages in heavy activities, such as carrying heavy weights (20 lb or more), strenuous farm work, or strenuous gardening.

99. Thinking about the things you usually did at **work** during the **last 12 months,** how would you describe the kind of physical activity you performed?

1 = Inactive
2 = Light
3 = Moderate
4 = Heavy

10. Thinking about the things you usually did at **home** during the **last 12 months,** how would you describe the kind of physical activity you performed?

1 = Inactive
2 = Light
3 = Moderate
4 = Heavy

101. Thinking about the things you usually did in your **leisure time** during the **last 12 months,** how would you describe the kind of physical activity you performed?

1 = Inactive
2 = Light
3 = Moderate
4 = Heavy

The next set of questions is about cigarette smoking.
Mark the box that best describes your experience with each statement.

102. Have you smoked at least 100 cigarettes in your entire life?

Note: 5 packs = 100 cigarettes

1 = Yes
2 = No (do not proceed)
3 = Don't know / Not sure (do not proceed)

103. Do you smoke cigarettes every day, some days, or not at all?

1 = Every day
2 = Some days
3 = Not at all (go to 106)
4 = Don't know / Not sure (do not proceed)

104. During the past 12 months, have you stopped smoking for one day or longer because you were trying to quit smoking?

1 = Yes
2 = No (do not proceed)
3 = Don't know / Not sure (do not proceed)

105. How long has it been since you last smoked a cigarette, even one or two puffs?

1 = Within the past month (less than 1 month ago)
2 = Within the past 3 months (1 month but less than 3 months ago)

3 = Within the past 6 months (3 months but less than 6 months ago)
4 = Within the past year (6 months but less than 1 year ago)
5 = Within the past 5 years (1 year but less than 5 years ago)
6 = Within the past 10 years (5 years but less than 10 years ago)
7 = 10 years or more
8 = Don‘t know / Not sure

Center for Epidemiologic Studies Depression Scale

Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way **during the past week**.

1. I was bothered by things that usually didn't bother me.

   __ Rarely or none of the time (less than 1 day)
   __Some or a little of the time (1-2 days)
   __ Occasionally or a moderate mount of time (3-4 days)
   __ Most or all the time (5-7 days)

2. I did not feel like eating; my appetite way poor.

   __ Rarely or none of the time (less than 1 day)
   __Some or a little of the time (1-2 days)
   __ Occasionally or a moderate mount of time (3-4 days)
   __ Most or all the time (5-7 days)

3. I felt that I could not shake off the blues even with help from my family or friends.
   __ Rarely or none of the time (less than 1 day)
   __Some or a little of the time (1-2 days)
   __ Occasionally or a moderate mount of time (3-4 days)
   __ Most or all the time (5-7 days)

4. I felt I was just as good as other people.
   __ Rarely or none of the time (less than 1 day)
   __Some or a little of the time (1-2 days)
   __ Occasionally or a moderate mount of time (3-4 days)
   __ Most or all the time (5-7 days)

5. I had trouble keeping my mind on what I was doing.
   __ Rarely or none of the time (less than 1 day)
   __Some or a little of the time (1-2 days)
   __ Occasionally or a moderate mount of time (3-4 days)
   __ Most or all the time (5-7 days)

6. I felt depressed.
   __ Rarely or none of the time (less than 1 day)
   __Some or a little of the time (1-2 days)
   __ Occasionally or a moderate mount of time (3-4 days)
   __ Most or all the time (5-7 days)

7. I felt that everything I did was an effort.

__ Rarely or none of the time (less than 1 day)
__Some or a little of the time (1-2 days)
__ Occasionally or a moderate mount of time (3-4 days)
__ Most or all the time (5-7 days)

8. I felt hopeful bout the future.
__ Rarely or none of the time (less than 1 day)
__Some or a little of the time (1-2 days)
__ Occasionally or a moderate mount of time (3-4 days)
__ Most or all the time (5-7 days)

9. I thought my life had been a failure.
__ Rarely or none of the time (less than 1 day)
__Some or a little of the time (1-2 days)
__ Occasionally or a moderate mount of time (3-4 days)
__ Most or all the time (5-7 days)

10. I felt fearful.
__ Rarely or none of the time (less than 1 day)
__Some or a little of the time (1-2 days)
__ Occasionally or a moderate mount of time (3-4 days)
__ Most or all the time (5-7 days)

11. My sleep was restless.
__ Rarely or none of the time (less than 1 day)
__Some or a little of the time (1-2 days)
__ Occasionally or a moderate mount of time (3-4 days)
__ Most or all the time (5-7 days)

12. I was happy.
__ Rarely or none of the time (less than 1 day)
__Some or a little of the time (1-2 days)
__ Occasionally or a moderate mount of time (3-4 days)
__ Most or all the time (5-7 days)

13. I talked less than usual.
__ Rarely or none of the time (less than 1 day)
__Some or a little of the time (1-2 days)
__ Occasionally or a moderate mount of time (3-4 days)
__ Most or all the time (5-7 days)

14. I felt lonely.
__ Rarely or none of the time (less than 1 day)
__Some or a little of the time (1-2 days)
__ Occasionally or a moderate mount of time (3-4 days)
__ Most or all the time (5-7 days)

15. People were unfriendly.
__ Rarely or none of the time (less than 1 day)
__Some or a little of the time (1-2 days)
__ Occasionally or a moderate mount of time (3-4 days)
__ Most or all the time (5-7 days)

16. I enjoyed life.
__ Rarely or none of the time (less than 1 day)
__Some or a little of the time (1-2 days)
__ Occasionally or a moderate mount of time (3-4 days)
__ Most or all the time (5-7 days)

17. I had crying spells.
__ Rarely or none of the time (less than 1 day)
__Some or a little of the time (1-2 days)
__ Occasionally or a moderate mount of time (3-4 days)
__ Most or all the time (5-7 days)

18. I felt sad.
__ Rarely or none of the time (less than 1 day)
__Some or a little of the time (1-2 days)
__ Occasionally or a moderate mount of time (3-4 days)
__ Most or all the time (5-7 days)

19. I felt that people dislike me.
__ Rarely or none of the time (less than 1 day)
__Some or a little of the time (1-2 days)
__ Occasionally or a moderate mount of time (3-4 days)
__ Most or all the time (5-7 days)

20. I could not get “going.”
__ Rarely or none of the time (less than 1 day)
__Some or a little of the time (1-2 days)
__ Occasionally or a moderate mount of time (3-4 days)
__ Most or all the time (5-7 days)

Behavioral Risk Factor Surveillance Questionnaire –Exercise/Physical activity

The next few questions are about exercise, recreation, or physical activities other than your regular job duties.

During the past month, other than your regular job, did you participate in any physical activities or exercises such as running, calisthenics, golf, gardening, or walking for exercise?

___ Yes
___ No
___ Don't Know/Not sure

What type of physical activity or exercise did you spend the most time doing during the past month?

___
___ Don't Know/Not sure

How many times per week or per month did you take part in this activity during the past month?

___ Times per week
___ Times per month
___ Don't Know/Not sure

And when you took part in this activity, for how many minutes or hours did you usually keep at it?

_:_ Hours and minutes
___ Don't Know/Not sure

What other type of physical activity gave you the next most exercise during the past month?

___
___ No other activity
___ Don't Know/Not sure

How many times per week or per month did you take part in this activity during the past month?

___ Times per week
___ Times per month
___ Don't Know/Not sure

And when you took part in this activity, for how many minutes or hours did you usually keep at it?

_:_ Hours and minutes
___ Don't Know/Not sure

Modified-Patient Perceived Involvement in Care Scale

1. My healthcare provider (HCP) doesn't like to spend time talking about treatment options.

1 = All of the time 2 3 4 5 = Never

2. My HCP doesn't like it when I ask questions.

1 = All of the time 2 3 4 5 = Never

3. My HCP focuses on just one or two topics during the medical appointments so it's hard for me to bring up other issues or concerns that I may have.

1 = All of the time 2 3 4 5 = Never

4. I find it hard to talk with my HCP because he/she is always in such a hurry.

1 = All of the time 2 3 4 5 = Never

5. My HCP spends little time explaining treatment options to me.

1 = All of the time 2 3 4 5 = Never

6. My HCP gives me a complete explanation for my medical symptoms or treatment.

1 = All of the time 2 3 4 5 = Never

7. I ask my HCP to explain the treatment or procedure in greater detail.

1 = All of the time 2 3 4 5 = Never

8. I ask my HCP for recommendations about my medical symptoms.

1 = All of the time 2 3 4 5 = Never

9. I usually go into great detail about my medical symptoms.

1 = All of the time 2 3 4 5 = Never

10. I ask my HCP a lot of questions about my medical symptoms.

1 = All of the time 2 3 4 5 = Never

11. My HCP asks me what I believe is causing my medical symptoms.

1 = All of the time 2 3 4 5 = Never

12. I express doubts about the tests or treatment that my HCP recommended.

1 = All of the time 2 3 4 5 = Never

13. I suggest a certain kind of medical treatment to HCP.

1 = All of the time 2 3 4 5 = Never

14. I insist on a particular kind of test or treatment for my symptoms.

1 = All of the time 2 3 4 5 = Never

15. I give my opinion about the type(s) or test(s) or treatment(s) that my HCP recommended.

1 = All of the time 2 3 4 5 = Never

16. I talk about pain symptoms regardless of my HCP's reactions when I do so.

1 = All of the time 2 3 4 5 = Never

17. I ask questions regardless of my HCP's reaction to them.

1 = All of the time 2 3 4 5 = Never

18. My HCP asks me whether I agree with his/her decisions.

1 = All of the time 2 3 4 5 = Never

19. My HCP encourages me to talk about personal concerns related to my symptoms.

1 = All of the time 2 3 4 5 = Never

20. My HCP encourages me to give my opinion about my medical treatment.

1 = All of the time 2 3 4 5 = Never

Pittsburgh Sleep Quality Index

INSTRUCTIONS:
The following questions relate to your usual sleep habits during the past month only.

Your answers should indicate the most accurate reply for the majority of days and nights in the past month. Please answer all questions.

1. During the past month, what time have you usually gone to bed at night?
BED TIME _____

2. During the past month, how long (in minutes) has it usually taken you to fall asleep each night?
NUMBER OF MINUTES _____

3. During the past month, what time have you usually gotten up in the morning?
GETTING UP TIME _____

4. During the past month, how many hours of actual sleep did you get at night? (This may be different than the number of hours you spent in bed.)
HOURS OF SLEEP PER NIGHT _____

For each of the remaining questions, check the one best response. Please answer all questions.
5. During the past month, how often have you had trouble sleeping because you . . .
a) Cannot get to sleep within 30 minutes
Not during the past month_____
Less than once a week_____
Once or twice a week_____
Three or more times a week_____

b) Wake up in the middle of the night or early morning
Not during the past month_____
Less than once a week_____
Once or twice a week_____
Three or more times a week_____

c) Have to get up to use the bathroom
Not during the past month_____
Less than once a week_____
Once or twice a week_____
Three or more times a week_____

d) Cannot breathe comfortably
Not during the past month_____

Less than once a week_____
Once or twice a week_____
Three or more times a week_____

e) Cough or snore loudly
Not during the past month_____
Less than once a week_____
Once or twice a week_____
Three or more times a week_____

f) Feel too cold
Not during the past month_____
Less than once a week_____
Once or twice a week_____
Three or more times a week_____

g) Feel too hot
Not during the past month_____
Less than once a week_____
Once or twice a week_____
Three or more times a week_____

h) Had bad dreams
Not during the past month_____
Less than once a week_____
Once or twice a week_____
Three or more times a week_____

i) Have pain
Not during the past month_____
Less than once a week_____
Once or twice a week_____
Three or more times a week_____

j) Other reason(s), please describe

How often during the past month have you had trouble sleeping because of this?
Not during the past month_____
Less than once a week_____
Once or twice a week_____
Three or more times a week_____

6. During the past month, how would you rate your sleep quality overall?
Very good _____
Fairly good _____

Fairly bad _____
Very bad _____

7. During the past month, how often have you taken medicine to help you sleep (prescribed or "over the counter")?
Not during the past month_____
Less than once a week_____
Once or twice a week_____
Three or more times a week_____

8. During the past month, how often have you had trouble staying awake while driving, eating meals, or engaging in social activity?
Not during the past month_____
Less than once a week_____
Once or twice a week_____
Three or more times a week_____

9. During the past month, how much of a problem has it been for you to keep up enough enthusiasm to get things done?
No problem at all _____
Only a very slight problem _____
Somewhat of a problem _____
A very big problem _____

10. Do you have a bed partner or roommate?
No bed partner or roommate _____
Partner/room mate in other room _____
Partner in same room, but not same bed _____
Partner in same bed _____

If you have a roommate or bed partner, ask him/her how often in the past month you have had . . .
a) Loud snoring
Not during the past month_____
Less than once a week_____
Once or twice a week_____
Three or more times a week_____

b) Long pauses between breaths while asleep
Not during the past month_____
Less than once a week_____
Once or twice a week_____
Three or more times a week_____

c) Legs twitching or jerking while you sleep
Not during the past month_____

Less than once a week_____
Once or twice a week_____
Three or more times a week_____

d) Episodes of disorientation or confusion during sleep
Not during the past month_____
Less than once a week_____
Once or twice a week_____
Three or more times a week_____

e) Other restlessness while you sleep; please describe_____

Not during the past month_____
Less than once a week_____
Once or twice a week_____
Three or more times a week_____

Self-perceived health

In general, how would you rate your health?

a. Excellent
b. Very good
c. Good
d. Fair
e. Poor

Social Desirability Scale Short Form

Listed below are a number of statements concerning personal attitudes and traits. Read each item and decide whether the statement is *true* or *false* as it pertains to you personally.

1. I like to gossip at times.
    A. True
    B. False

2. There have been occasions when I took advantage of someone.
    A. True
    B. False

3. I'm always willing to admit it when I make a mistake.
    A. True
    B. False

4. I always try to practice what I preach.
    A. True
    B. False

5. I sometimes try to get even rather than forgive and forget.
    A. True
    B. False

6. At times I have really insisted on having things my own way.
    A. True
    B. False

7. There have been occasions when I felt like smashing things.
    A. True
    B. False

8. I never resent being asked to return a favor.
    A. True
    B. False

9. I have never been irked when people expressed ideas very different from my own.
    A. True
    B. False

10. I have never deliberately said something that hurt someone's feelings.
    A. True
    B. False

Thank you for your interest in participating in our study. The following is a list of questions that will determine your eligibility for this study. We will email you within a few days after your completion of this screener.

1. Are you age 21 or over?
   A. Yes
   B. No

2. What is your gender?
   A. Male
   B. Female

3. Are you able to access the Internet when needed?
   A. Yes
   B. No

4. Are you able to use the Internet by yourself (without help)?
   A. Yes
   B. No

5. Have you been diagnosed with any form of cancer?
   A. Yes
   B. No
   If yes, please specify the type of cancer you were diagnosed with:
   _____

6. Have you been diagnosed with breast cancer?
   A. Yes
   B. No

7. Were you diagnosed with stage 0 breast cancer?
   A. Yes
   B. No

8. Were you diagnosed with stage IV (metastatic) breast cancer?
   A. Yes
   B. No

9. Did you complete primary cancer treatment (defined as surgery, radiation therapy, and/or chemotherapy) between 1 day and 1 year ago?
   A. Yes
   B. No

10. What is an email address where you can be contacted at for the purpose of this study?

    _____

Please note that within the next few days, we will be emailing you from the following email address: briana.todd@usuhs.edu. Please ensure that your email address allows this email address to bypass any filter settings in your email account. Thank you for your interest in our study.

Appendix D: Informed consent

Consent for Voluntary Participation in a Research Study

1. INTRODUCTION OF THE STUDY: You are being asked to be in a research study entitled, "Development of the Cancer Survivor Profile," at the Uniformed Services University (USU), Bethesda, Maryland. You are eligible to participate in this study if you are a female breast cancer survivor (stages I-III) within five years of completion of primary cancer treatment (surgery, chemotherapy, and/or radiation), this is your first cancer diagnosis, and are age 21 or older. Your participation is voluntary. Refusal to participate will not result in any punishment or loss of benefits to which you are otherwise permitted. Please read the information below, and ask questions about anything you do not understand, before deciding whether to take part in the study.

---

2. THE PURPOSE OF THE STUDY:

- The 5-year survival rate of breast cancer is 89%.
- Some breast cancer survivors experience late and long-term effects of cancer and its treatment, as well as difficulty navigating the health care system.
- This study will develop a self-report questionnaire that will be designed to help health care providers and breast cancer survivors identify and optimize a breast cancer survivor's knowledge and ability to access health services, symptom burden, function, and protective health behaviors.

3. THE PROCEDURES TO BE FOLLOWED:

Individuals meeting qualifications below may be asked to participate in the study.

You may qualify for the study based on the following:

- Adult female ages 21 or older.
- Computer/Internet access.
- Breast cancer survivor (stage I-III) between 1 day and 5 years since primary treatment (surgery, chemotherapy, and/or radiation) for breast cancer ended.

You are not qualified if you have any of the following:

- Any other cancer diagnoses.
- Was diagnosed with stage 0 or stage IV breast cancer

Participation in the study includes completing

1. Online questionnaire (approximately 45 minutes)
    a. If you start the questionnaire, but do not complete it, we will send up to two reminder emails reminding you to complete the questionnaire.

You may elect to not complete the survey and can respond to the email requesting that no additional emails be sent.

2. You will be asked to complete additional questions 2-weeks after your first date of participation (approximately 15 minutes)
    a. We will send two reminder emails to complete the addition questions, for a total of 3 emails.

Procedures

- All study material will be completed on this website.
- If you agree to participate in the study you will complete some questions (e.g., gender, age, cancer diagnosis) to determine if you are eligible.
- If you are eligible, you will next be asked to answer questions about symptom burden (e.g., fatigue, anxiety), function (e.g., work function, cognitive function), health behaviors (e.g., cigarette smoking, diet), and health service needs (e.g., patient-doctor communication, economic barriers to care).
- After you completing these questions you can provide contact information to receive a $10 Amazon gift card for your participation.
- Two weeks after your initial participation, we will email you to ask you to complete another set of questions about symptom burden, function, health behaviors, and health service needs. Your participation is again voluntary and no compensation will be provided.

4. DURATION OF THE STUDY

Approximately 45 minutes to 1 hour

5. **POSSIBLE BENEFITS TO YOU THAT MAY BE REASONABLY EXPECTED ARE:** This study is being conducted solely for the purpose of research and there will be no direct benefit to you from participating in this study. The information we learn may help us design a self-report assessment tool that can help manage and optimize the care of future breast cancer survivors.

6. DISCOMFORTS AND/OR RISKS THAT CAN BE REASONABLY EXPECTED ARE:

The risks associated with this study are minor

- You may find the questionnaires ask questions that may make you uncomfortable.
    - You may skip questions at any time.
    - Also, you may decline to participate at any time and/or withdraw your participation at any time by closing your web browser. As explained above, up to two reminder emails will automatically be sent to complete the questionnaire. However, you may respond to the email requesting that no additional emails be sent.
- You may experience fatigue while completing the questions
    - You may take breaks in between questions.

7. PRIVACY AND CONFIDENTIALITY:

- All information you provide as part of this study will be confidential and will be protected to the fullest extent provided by law.
- Information that you provide and other records related to this study will be accessible to those persons directly involved in conducting this study and members of the Uniformed Services University of the Health Sciences Institutional Review Board, which provides oversight for protection of human research volunteers.
- All questionnaires, results and forms will not have identifying information and will be kept in a restricted access, password protected computer, in a locked office. Data from questionnaires will be entered into a database in which individual responses are not identified.
- Paper copies of the data will not be kept.
- Personal information will be collected for payment purposes. This information will be kept separate from the database, in a password protected computer in a locked office at the Uniformed Services University of the Health Sciences.
- If you are a military member, please be advised that under Federal Law, a military member's confidentiality cannot be strictly guaranteed.

NOTE: You are free to withdraw this consent and to stop participating in this study at anytime for any reason.

8. COMPENSATION

- If you meet study eligibility, you will be given the option to receive a $10 Amazon gift card for completing the study.
- At the end of the study, you will be asked for some personal information (e.g., email address) in order to receive the gift card.
- This information will be stored separately from the study data and will be stored in a secure, password protected computer in a locked office with restricted access.

9. RECOURSE IN THE EVENT OF INJURY:

COMPENSATION TO YOU IF YOU ARE INJURED AND LIMITS TO YOUR MEDICAL CARE: This study should not entail any physical or mental risk beyond those described above. It is believed that complications arising from participation should not occur. If, for any reason, you feel that continuing this study would constitute a hardship for you, you may end your participation in the study at any time.

If at any time you believe you have suffered an injury or illness as a result of participating in this research project, contact the Director of Human Subjects Protection Program at the Uniformed Services University of the Health Sciences, Bethesda, Maryland 20814-4799 at (301) 295-9534. This office can review the matter with you. They can provide information about your rights as a research volunteer. They may also be able to identify resources available to you. If you believe the government or one of the government's employees (such as a military doctor) has injured you, a claim for damages (money) against the federal government (including the military) may be filed under the Federal Torts Claims Act. Information about judicial avenues of compensation is available from the University's General Counsel at (301) 295-3028.

10. CONTACT FOR QUESTIONS OR PROBLEMS: If you have questions about this research, you should contact **Briana Todd,** the person in charge of the study. Her phone number at USUHS is **(301)295-9659**. Even in the evening or on weekends, you can leave a message at that number. If you have questions about your rights as a research subject, you should call the Director of Human Research Protections Programs at USUHS at (301) 295-9534. He/she is your representative and has no connection to the researcher conducting this study.

STATEMENT BY PERSON AGREEING TO PARTICIPATE IN THIS RESEARCH PROJECT:

I have read this consent form and I understand the procedures to be used in this study and the possible risks, inconveniences, and/or discomforts that may be involved. All of my questions have been answered. I freely and voluntarily choose to participate. I understand that I may withdraw at any time.

By clicking on the "yes" button, you are agreeing that you have read the consent form and understand the procedures to be used in this study. You also agree that you freely and voluntarily choose to participate and understand that you may withdraw at anytime. If you wish you may print out a copy of this form for your records.

Yes, I agree to participate in this study.

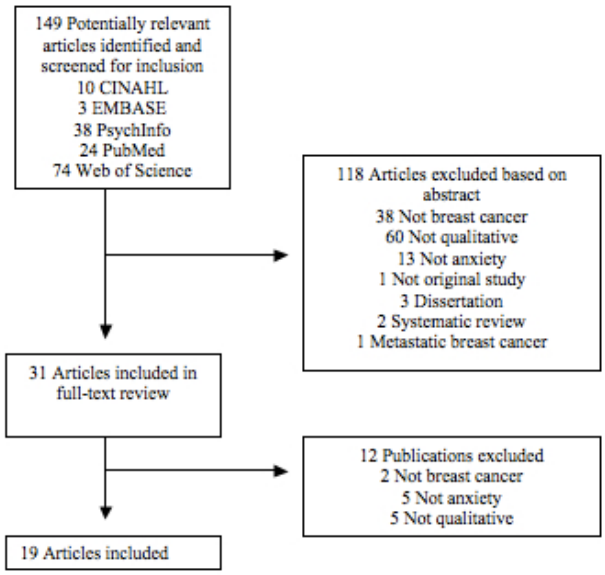
Appendix E: Preliminary Cancer Survivor Profile item source

Construct	Source
Fear of recurrence	Impact of Cancer, version 2 (101)
Fertility distress	The Fertility Problem Inventory (281)
Exercise/Physical activity	Postmenopausal Estrogen/Progesterone Intervention Activity Questionnaire (180)
Health information	Supportive Care Needs- Short Form (45)
Health competence	Perceived Health Competence Scale (334)
Work	Work Ability Index (368)
Economic demands	Quality of Life in Adult Cancer Survivors (20)
Patient-provider communication	Perceived Efficacy in Patient-Physician Interactions (246)
Cigarette smoking	Behavioral Risk Factors Surveillance Questionnaire (74)
Diet	Multifactor Screener (360)
Body Image	Impact of Cancer, Version 2 (101)
Sexual function	PROMIS Bank V1.0- Interest in Sexual Function, PROMIS Bank v1.0- Global Satisfaction with Sex Life, PROMIS Pool v1.0- Interfering Factors *
Pain	Pain Interference Short Form 8a
Sleep	Sleep Disturbance Short Form 8a, PROMIS SF v1.0- Sleep Related Impairment 8a
Fatigue	Fatigue Short Form 8a
Social isolation	Social Isolation-Short Form 8a, Emotional Support Short Form 8a, Instrumental Support-Short Form 8a
Depressive symptoms	Depression-Short Form 8a
Cognitive function	PROMIS v1.0 Applied Cognition-General Concerns- Short Form 8a
Anxiety	PROMIS Item Bank v1.0-Emotional Distress-Anxiety-Short Form 8a
Alcohol consumption	PROMIS SF v10- Alcohol: Negative Expectancies- Short Form 7a*

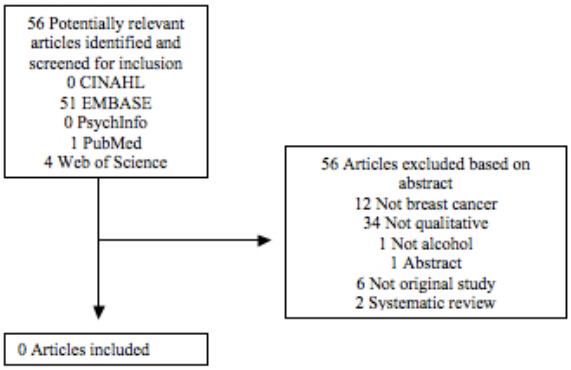
*Derived from PROMIS items, modified and used with the permission of the PROMIS Health Organization and the PROMIS Cooperative Group

Additional information on PROMIS measures can be found at www.NIHPROMIS.org (3)

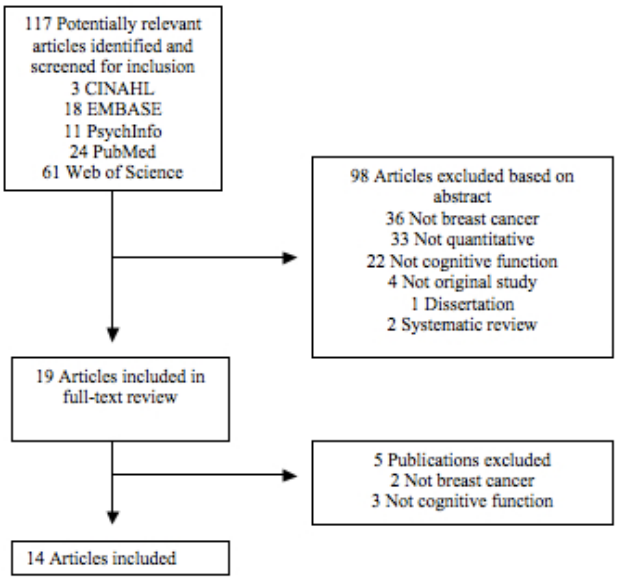
Appendix F. Flowcharts of search process: PROMIS



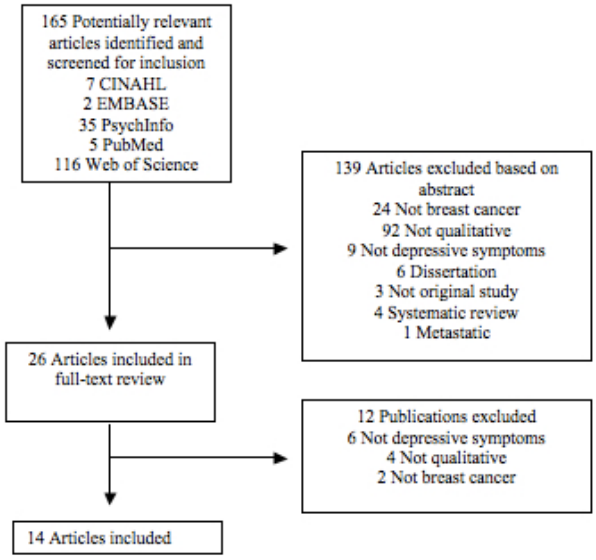
Appendix F Figure 1. Flowchart of search process for anxiety



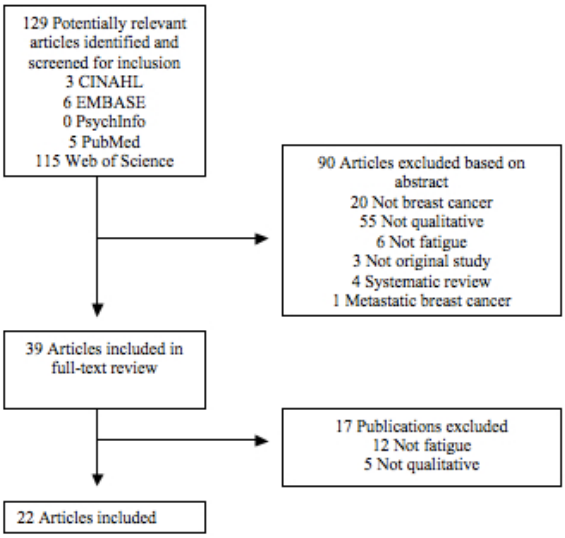
Appendix F Figure 2. Flowchart of search process for alcohol



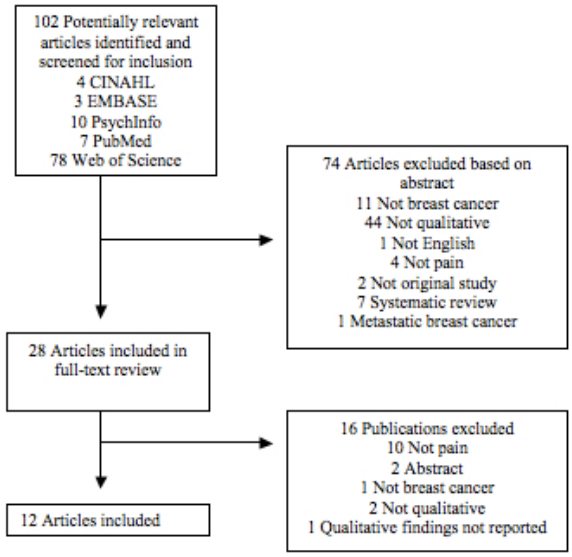
Appendix F Figure 3. Flowchart of search process for cognitive function



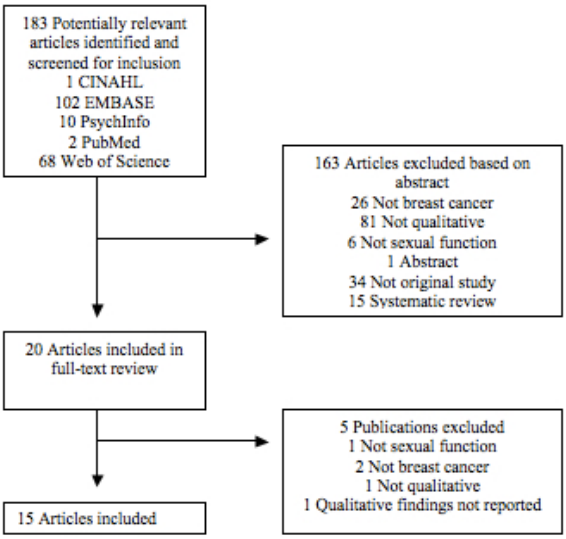
Appendix F Figure 4. Flowchart of search process for depressive symptoms



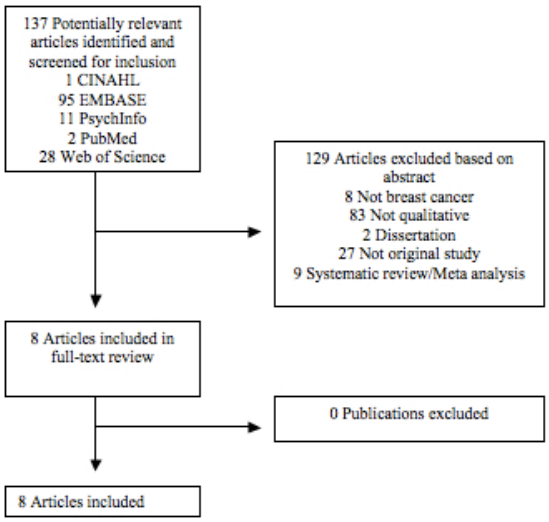
Appendix F Figure 5. Flowchart of fatigue selection process



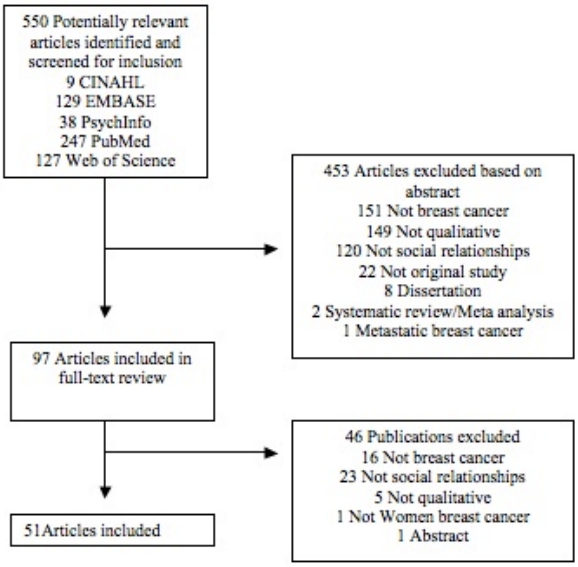
Appendix F Figure 6. Flowchart of search process for pain



Appendix F Figure 7. Flowchart of search process for sexual function



Appendix F Figure 8. Flowchart for search process of sleep



Appendix F Figure 9. Flowchart of search process for social relationships

Appendix G. Review of qualitative studies in breast cancer: Identification of themes

Appendix G1. Review of qualitative studies in breast cancer: Anxiety themes

Anxiety											
	Theme										
	Anxiety	**Fear**	**Anxiety Attacks**	**Stomach Symptoms**	**Cognitive**	**Health Anxiety**	**Irritability**	**Worry**	**Racing thoughts**	**Sleep**	**Loss of control**
Frequency	**79%**	**32%**	**5%**	5%	5%	**21%**	**11%**	**37%**	5%	11%	5%
Article											
Ashing et al., (17)	Anxiety	Fear about being positive	_____	_____	_____	_____	_____	_____	_____	_____	_____
Gaudine et al., (169)	Anxiety	Uncertainty Vulnerability	Anxiety attacks	Stomach sickness	Concentration	_____	_____	_____	_____	_____	_____
Morse et al., (269)	Anxiety	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____
Cox et al., (96)	Anxiety	_____	_____	_____	_____	Anxiety about medical tests	_____	_____	_____	_____	_____
Fatone et al., (132)	Anxiety	_____	_____	_____	_____		Irritability	Worry	_____	_____	_____
Flynn et al., (150)	Anxiety	_____	_____	_____	_____	_____	_____	_____	Racing thoughts about cancer	Interrupted sleep	
Loerzel et al., (241)	Anxiety	Uncertainty	_____	_____	_____	_____	Irritability	_____	_____	_____	_____
Galvan et al., (163)	“Anxiety	_____	_____	_____	_____	Anxiety about procedures	_____	_____	_____	_____	_____
Lopez-Class et al., (243)	Anxiety	_____	_____	_____	_____	Anxiety about medical appointments	_____	_____	_____	_____	_____
Lewis et al., (237)	Anxiety	_____	_____	_____	_____	_____	_____	Worry	_____	_____	_____
Bennet et al., (29)	Anxiety	Constant fear	_____	_____	_____	_____	_____	Worry	_____	_____	_____

Fleming et al., (147)	_____	_____	_____	_____	_____	_____	_____	Worry	_____	Worry about poor sleep	_____
Munir et al., (276)	Anxiety	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____
Salander et al., (324)	Anxiety	Vulnerable	_____	_____	_____	Anxiety about symptoms	_____	"Worry	_____	_____	_____
Tsai et al., (366)	_____	_____	_____	_____	_____	_____	_____	Worry	_____	_____	_____
Chung et al., (83)	Anxiety	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____
Browall et al., (51)	_____	Uncertainty	_____	_____	_____	_____	_____	Worry	_____	_____	_____
Nizamli et al., (285)	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____	Loss of control
Rosedale et al., (318)	Anxiety	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____

Note. Did not select sleep problems because of diagnostic overlap with sleep (another construct on the CSPro). Selected anxiety attacks due to the diagnostic criteria for anxiety disorders and the lack of diagnostic overlap with other constructs on the CSPro (13).

Appendix G2. Review of qualitative studies in breast cancer: Cognitive function themes

Cognitive Function											
	Theme										
	Concen-tration/ Attention	**Memory**	**Executive function**	**Confusion**	**Short-term memory**	**Word finding**	**Processing speed**	**Math**	**Fog**	**Visual spatial**	**Mental fluency**
Frequency	**64%**	**93%**	**50%**	7%	21%	**29%**	**21%**	7%	**21%**	7%	7%
Article											
Fleming et al., (147)	Concen-tration	Memory	_____	_____	_____	_____	_____	_____	_____	_____	_____
Munir et al., (275)	Attention	Memory	Executive function	_____	_____	_____	_____	_____	_____	_____	_____
Fatone et al., (132)	_____	Memory	_____	Confusion	Short-term memory	_____	_____	_____	_____	_____	_____
Cappiello et al., (63)	Concen-tration	Memory	Multi-tasking	_____	_____	_____	_____	_____	_____	_____	_____
Tighe et al., (363)	_____	Memory	_____	_____	_____	_____	_____	_____	_____	_____	_____
Rosedale et al., (318)	Concen-tration/ Attention	Memory	_____	_____	_____	_____	_____	_____	Not sharp	_____	_____
Bennett et al., (29)	Concen-tration/ Attention	Memory	_____	_____	Short-term memory	Word finding/	_____	_____	_____	_____	_____
Landmark et al., (235)	_____	Memory	_____	_____	_____	_____	_____	_____	_____	_____	_____
Boykoff et al., (46)	_____	Memory	Multi-tasking	_____	_____	Word finding	Processing speed	Math	_____	_____	_____
Myers et al., (277)	Concen-tration/ Attention	Memory/ Misplacing items	Multi-tasking	_____	Short-term memory	Word finding	_____	_____	_____	_____	_____
Munir et al., (275)	_____	Memory	Multi-tasking	_____	_____	_____	_____	_____	Fog	_____	_____

Tamming a et al., (354)	Attention	Retrieval memory	Executive function	_____	_____	_____	Processing speed	_____	_____	_____	_____
Downie et al., (117)	Concen-tration/	Misplacing items	Planning/ Multi-tasking	_____	Short-term memory	Word finding/	Processing speed	_____	Fog/Not sharp	Visual spatial	Mental fluency
Chan et al., (76)	Concen-tration/ Attention	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____

Note. Selected processing speed and fogginess over short-term memory (three-way tie) because already have question about memory. Dash indicates theme not represented in study.

Appendix G3. Review of qualitative studies in breast cancer: Fatigue themes

Fatigue										
	Theme									
	Loss of energy	**Fatigued**	**Tired**	**Physical sensation**	**Sleep**	**Rest**	**Mobility**	**Unpredictability**	**Pervasiveness**	**Overwhelming**
Frequency	**45%**	**45%**	**55%**	9%	14%	**27%**	9%	**23%**	**32 %**	23%
Article										
Rosedale et al., (318)	Loss of energy	_____	_____	_____	_____	Rest	_____	_____	_____	_____
Wu et al., (394)	Energy	_____	Tired		Unrefreshing	Rest	Loss of function	Sudden	Constant	Overwhelming
Capiello et al., (63)	_____	_____	_____	_____	_____	_____	_____	Not anticipated	Constant	Overwhelming
Myers et al., (277)	_____	_____	_____	_____	_____	Nap	_____	_____	_____	_____
Avis et al., (20)	Lack energy	Fatigued	Tired	_____	_____	_____	_____	_____	_____	_____
Bennett et al., (29)	Lack energy/ No energy	Fatigue	Tired	_____	Unrefreshing	_____	_____	_____	_____	_____
Blaney et al., (34)	_____	_____	_____	Weak/ Exhausted	_____	_____	_____	Lack of control	Constant	Overwhelming
Chan et al., (76)	Energy	_____	_____	_____	_____	_____	_____	_____	_____	_____
Chung et al., (83)	_____	_____	Tired/Spent	_____	_____	_____	_____	_____	Pervasive	_____
Fleming et al., (147)	_____	Fatigue	Tired	_____	_____	_____	_____	_____	Constant	_____
Flynn et al., (150)	No energy	Fatigue	Tired	_____	_____	Nap	_____	_____	_____	_____
Landmark et al., (235)	Energy	_____	_____	_____	_____	_____	_____	_____	_____	_____
Loerzel et al., (241)	_____	Fatigue	_____	_____	_____	_____	_____	_____	_____	_____
Rosman et al., (319)	Loss of energy	_____	Tired	Heaviness/ Paralysis	_____	Rest	_____	Unpredicatable	Constant	_____
Tighe et al., (363)	_____	_____	Tired	_____	_____	_____	_____	_____	_____	Overwhelming
Tsai et al., (366)	_____	_____	Tired	_____	_____	_____	_____	_____	_____	_____
Binkley et al., (31)	Loss of energy	Fatigue	_____	_____	_____	_____	Loss of function	_____	_____	Overwhelming
Chung et al., (83)	_____	Fatigued	Tired	_____	_____	_____	_____	_____	Pervasive	_____

Tamminga et al., (354)	_____	Fatigue	_____	_____	_____	_____	_____	Fluctuate	_____	_____
Fatone et al., (132)	_____	Fatigue	Tired	_____	_____	_____	_____	_____	_____	_____
Oxlad et al., (289)	Low energy	_____	Tired	_____	_____	_____	_____	_____	_____	_____
Grimsbo et al., (181)	_____	Fatigue/ Lethargic	_____	_____	Unrefreshing	Rest	_____	_____	_____	_____

Note. Selected Unpredictability over Overwhelming (tied) because more likely to help with the management of unpredictability nature of fatigue. Dash indicates theme not represented in study.

Appendix G4. Review of qualitative studies in breast cancer: Pain themes

Pain																						
	Theme																					
Frequency	25%	**25%**	25%	**33%**	25%	8%	8%	**50%**	25%	17%	25%	25%	8%	8%	25%	25%	**33%**	17%	17%	17%	**33%**	8%	17%
Article																							
	Shoulder	**Mobility**	**Back**	**Intensity**	**Arm**	**Hand**	**Hip**	**Joint**	**Function**	**Affective**	**Bone**	**Muscle**	**Post-operative**	**Aching**	**Numb**	**Heavy**	**Burning**	**Tight**	**Stiff**	**Discomfort**	**Sharp**	**Dull**	**Sore**
Binkley et al., (31)	Shoulder	Mobility limitations	Upper back	Extreme	____	____	____	____	____	____	____	____	____	____	____	____	____	____	____	____	____	____	____
Fleming et al., (147)	____	____	____	Heigh-tened	____	____	____	____	____	____	____	____	____	____	____	____	____	____	____	____	____	____	____
Fatone et al., (132)	____	____	Back	____	Arm	Hand	Hip	Joint	Function limitations	Upsetting	____	____	____	____	____	____	____	____	____	____	____	____	____
Ingram et al., (214)	Shoulder	Range of motion	____	____	Arm	____	____	Joint	____	____	Bone	Muscle	Post-operative	____	____	____	____	____	____	____	____	____	____
Thomas-MacLean et al., (359)	____	Mobility limitations	____	____	____	____	____	____	____	____	____	____	____	Aching	Numb	Heavy	Burning/ Tingling	Tight	____	____	____	____	____
Cappiello et al., (63)	____	____	____	____	____	____	____	Joint	____		____	____	____	____	____	Cement	____	____	Stiff	Discomfort	____	____	____
Ferrell et al., (138)	____	____	____	____	____	____	____	____	____	Frightening	____	____	____	____	____	____	____	____	____	____	Sharp	Dull	____
Ferrell, et al., (139)	Shoulder	____	Back	Excruciating	____	____	____	Joint	____	____	Bone	____	____	____	Numb	____	Burning/ Fire	____	Stiff	____	Sharp/ Jabs	____	Sore
Flynn et al., (150)	____	____	____	____	____	____	____	Joint	Walking	____	Bone	Muscle	____	____	Numb	____	____	____	____	____		____	____
Fu et al., (157)	____	____	____	____	____	____	____	____	____	____	____	____	____	____	____	Heavy	Burning	Tight/ Rigid	____	____	Sharp/ Stab	____	Sore

Im et al, (213)	——	——	——	Inten-se	——	——	——	——	——	——	——	——	——	——	——	——	——	——	——	——	——	——	——
Royer et al., (320)	——	——	——	——	Arm	——	——	Joint	Funct-ional limita-tions	——		Musc-le	——	——	——	——	——	——	——	——	——	——	——

Note. Dash indicates theme not represented in study.

Appendix G5. Review of qualitative studies in breast cancer: Sexual function themes

Sexual Function													
	Theme												
Frequency	13%	33%	**60%**	7%	20%	13%	7%	13%	13%	**20%**	**33%**	**27%**	13%
Article													
	Intimacy	**Vaginal dryness**	**Lack of interest**	**Tired**	**Frequency**	**Sexual arousal**	**Sensation**	**Enjoyment**	**Avoidance**	**Attractive**	**Libido**	**Pain**	**Orgasm**
Chung et al., (83)	Intimacy	Vaginal dryness	Interest	Tired	_____	_____	_____	_____	Avoidance	_____	_____	_____	_____
Tighe et al., (363)	_____	_____	_____	_____	Frequency	_____	_____	_____	_____	_____	_____	_____	_____
Rosedale et al., (318)	_____	Vaginal dryness	Desire	_____	Frequency	Sexual arousal	Sensation	Enjoyment	_____	_____	_____	_____	_____
Fatone et al., (132)	Intimacy/ Affection	Vaginal dryness	Desire/ Interest	_____	_____	_____	_____	_____	Avoidance	Attractive/ Feminine	_____	_____	_____
Cappiello et al., (63)	_____	_____	Interest	_____	_____	_____	_____	_____	_____	_____	Libido/ Drive	_____	_____
Beatty et al., (26)	_____	_____	Interest	_____	Frequency	_____	_____	_____	_____	_____	_____	_____	_____
Howard et al., (211)	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____	Libido	Pain	_____
Klaeson et al., (226)	_____	_____	Desire	_____	_____	_____	_____	Enjoyment	_____	_____	_____	_____	Excitement
Oxlad et al., (289)	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____	Drive	_____	_____
Lopez-Class et al., (243)	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____	Libido	_____	_____
Thewes et al., (357)	_____	Vaginal dryness	_____	_____	_____	_____	_____	_____	_____	Sexuality	Libido	_____	_____
Lewis et al., (237)	_____	Vaginal dryness	_____	_____	_____	_____	_____	_____	_____	Attractive	_____	_____	_____
Archibald et al., (16)	_____	_____	Desire	_____	_____	Sexual arousal	_____	_____	_____	_____	_____	Pain	Orgasms
Tam Ashing et al., (353)	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____
Ashing-Giwa et al., (17)	_____	_____	Sexual desire	_____	_____	_____	_____	_____	_____	_____	_____	Pain	_____

Note. Selected constructs that were general due to CSPro's intention (i.e., general screening measure). Did not look at frequency or vaginal dryness because of specificity of questions. Dash indicates theme not represented in study.

Appendix G6. Review of qualitative studies in breast cancer: Sleep themes

Sleep												
	Theme											
Frequency	**38%**	25%	**63%**	13%	**25%**	**25%**	**25%**	13%	**25%**	13%	13%	13%
Article												
	Decreased amount	**Quality**	**Sleep disturbance**	**Poor sleep**	**Tired**	**Nighttime awakenings**	**Daytime naps**	**Concern about partner**	**Restless-ness**	**Sleep onset**	**Dreams**	**Intrusive thoughts disrupt sleep**
Tsai et al., (366)	Loss	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____
Tamminga et al., (354)	_____	Quality	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____
Fleming et al., (147)	Loss	Quality	Disturbance	Poor	Tired	Awakenings	Naps	Partner concern	Restless	_____	_____	_____
Fatone et al., (132)	_____	_____	Difficulty	_____	_____	_____	_____	_____	_____	_____	_____	_____
Flynn et al., (150)	Duration	_____	_____	_____	Tired/ Sleepy	Continuity	Naps	_____	Movement	Onset	Dreams	_____
Cappiello et al., (63)	_____	_____	Difficulty	_____	_____	_____	_____	_____	_____	_____	_____	Cognitions
Loerzel et al., (241)	_____	_____	Disturbance	_____	_____	_____	_____	_____	_____	_____	_____	_____
Beatty et al., (26)	_____	_____	Difficulty	_____	_____	_____	_____	_____	_____	_____	_____	_____

Note. Did not select Quality because the other categories tied with Quality category describe sleep quality. Dash indicates theme not represented in study.

Appendix G7. Review of qualitative studies in breast cancer: Social relationships themes

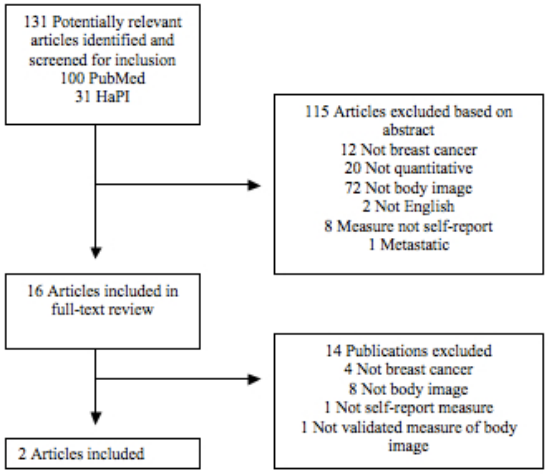
Social Relationships												
	Theme											
Frequency	**22%**	**39%**	6%	24%	10%	2%	6%	**16%**	**22%**	**12%**	10%	1**4%**
Article												
	Significant other strain	**Lack of support**	**Negative coping**	**Positive effects**	**Shared experience**	**Needing help**	**Tangible support**	**Emotional support**	**Lonely**	**Difficulty relating to others**	**Informational support**	**Relationship changes**
Tighe et al., (363)	Marital strain	Lack of support	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____
Henderson et al., (195)	_____	Lack of support	Negative experience	Family support	_____	_____	_____	_____	_____	_____	_____	_____
Howard et al., (196)	_____	Lack of support		Family support	_____	_____	_____	_____	_____	_____	_____	_____
Doumit et al., (116)	_____	_____	Negative experience	Positive support	Shared experience	_____	_____	_____	_____	_____	_____	_____
Fergus et al., (134)	Partner problems	_____	_____	_____	_____	Need help	_____	_____	_____	_____	_____	_____
Gonzalez et al., (171)	Poor partner support	_____	_____	_____	Cancer population	_____	Tangible support	Emotional support	_____	_____	_____	_____
Chung et al., (83)	_____	Lack of support	_____	Positive support	_____	_____	_____	_____	_____	_____	_____	_____
Rosedale et al., (318)	_____	_____	_____	_____	_____	_____	_____	_____	Lonely/ Isolated	Relating to others	_____	_____
Fleming et al., (147)	_____	_____	_____	_____	_____	_____	_____	_____	Isolated	Relating to others	_____	_____
Carter et al., (68)	Partner problems	_____	_____	_____	_____	_____	_____	_____	Isolated	_____	_____	_____
Alqaissi et al., (7)	_____	_____	Negative experience	Positive support	_____	_____	_____	_____	_____	_____	_____	_____
Beatty et al., (26)	Poor partner support	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____
Dolce et al., (115)	_____	_____	_____	_____	_____	_____	_____	Emotional support	_____	_____	Informational support	_____
Klaeson et al., (226)	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____	Relationship changes
Kobetz et al., 2011 (230)	_____	Low support	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____
Landmark et al., (235)	_____	_____	_____	_____	Support groups	_____	_____	Emotional support	_____	_____	Informational support	_____
Livaudais et al., (240)	Marital support	_____	_____	_____	_____	_____	_____	_____	Isolation	_____	_____	_____
Marbach et al., (248)	_____	Low support	_____	_____	Support groups	_____	_____	Emotional support	_____	_____	_____	_____

Mikkelsen et al., (262)	_____	Low support	_____	_____	Support groups	_____	_____	_____	Isolation	Relating to others	_____	_____
Mokuau et al., (266)	_____	_____	_____	Family support	_____	_____	_____	_____	_____	_____	Informational support	_____
Morgan et al., (268)	_____	_____	_____	Spousal support	_____	_____	_____	_____	_____	_____	_____	_____
Oxlad et al., (289)	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____	Relationship changes
Rosedale et al., (317)	_____	Low support		_____	_____	_____	_____	_____	Lonely	_____	_____	_____
Shaha et al., (328)	_____	_____	_____	_____	_____	_____	_____	_____	Isolated	Relating to others	_____	_____
Shannon et al., (329)	_____	_____	_____	Positive support	_____	_____	_____	_____	_____	_____	_____	_____
Sprung et al., (344)	Partner problems	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____
Westman et al., (385)	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____	Relationship changes
Wilmoth et al., (388)	Partner problems	Low support	_____	_____	_____	_____	_____	_____	_____	_____	_____	Relationship changes
Yoo et al., (396)	_____	_____	_____	_____	_____	_____	Tangible support	Emotional support	_____	_____	_____	_____
Lewis et al., (237)	_____	Low family support	_____	_____	_____	_____	_____	_____	Lonely/ Isolated	_____	_____	_____
Buki et al., (54)	_____	Low support	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____
Galvan et al. (163)	Poor partner support	_____	_____	_____	_____	_____	_____	_____	_____	_____	Informational support	_____
Thompson et al., (361)	_____	Low support	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____
Snyyder et al., (338)	_____	_____	_____	Positive support	_____	_____	_____	_____	_____	_____	_____	_____
Boykoff et al., (46)	_____	Low support	_____	_____	_____	_____	_____	_____	_____	Relating to others	_____	_____
da Silva et al., (105)	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____	Relationship changes
Hamilton et al., (187)	_____	Low support	_____	_____	_____	_____	_____	_____	_____	_____	_____	Lost friends
Mosavel et al., (270)	_____	_____	_____	_____	_____	_____	Tangible support	_____	_____	_____	_____	_____
Teleghani et al., (356)	_____	_____	_____	Spousal support	_____	_____	_____	_____	_____	_____	_____	_____
White et al., (386)	_____	_____	_____	Partner support	_____	_____	_____	_____	_____	_____	_____	_____
Lopez-Class et al., (243)	Male partner problems	_____	_____	_____	_____	_____	_____	Emotional support	Lonely/ Isolated	_____	_____	_____
Roberts et al., (313)	_____	_____	_____	Positive support	_____	_____	_____	_____	_____	_____	_____	_____

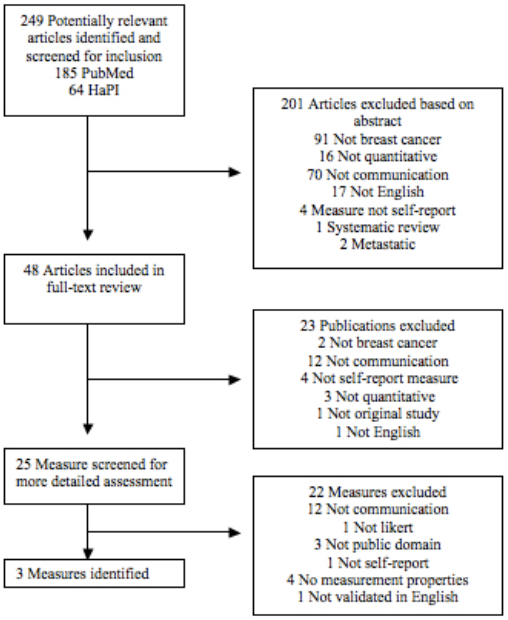
Tsuchiya et al., (367)	_____	Low support	_____	_____	_____	_____	_____	_____	_____	Relating to others	_____	_____
Wilson et al., (390)	_____	Low support	_____	_____	_____	_____	_____	Emotional support	_____	_____	_____	_____
Mellon et al., (257)	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____	Communica-tion changes
Ridner et al., (311)	_____	_____	_____	_____	_____	_____	_____	_____	Isolated	Relating to others	_____	_____
Gooden et al., (173)	_____	_____	_____	_____	_____	_____	_____	Emotional support	_____	_____	Informational support	_____
Sutton et al., (351)	_____	_____	_____	Partner support	_____	_____	_____	_____	_____	_____	_____	_____
Browall et al., (51)	Poor partner support	Low support	_____	_____	_____	_____	_____	_____	Lonely	_____	_____	_____
Gray et al., (179)	_____	Low support	_____	_____	_____	_____	_____	_____	_____	_____	_____	_____
Thewes et al., (357)	_____	_____	_____	_____	_____	_____	_____	_____	Isolated	_____	_____	_____

Note. Did not select Positive because purpose of CSPro is to focus on areas in need of intervention. Dash indicates theme not represented in study.

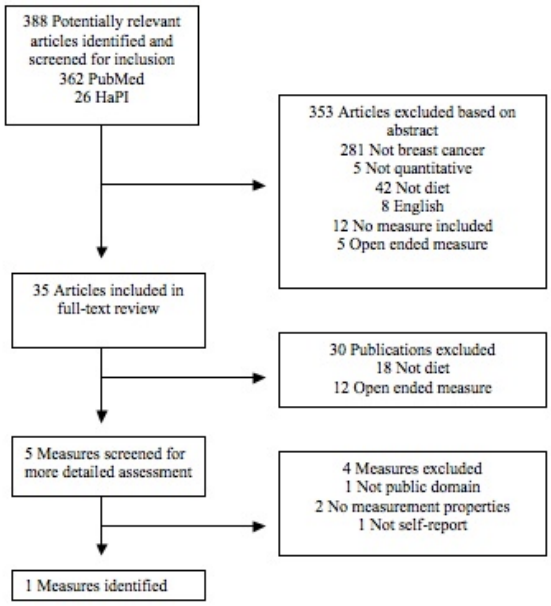
Appendix H. Flowcharts of search process: Non-PROMIS



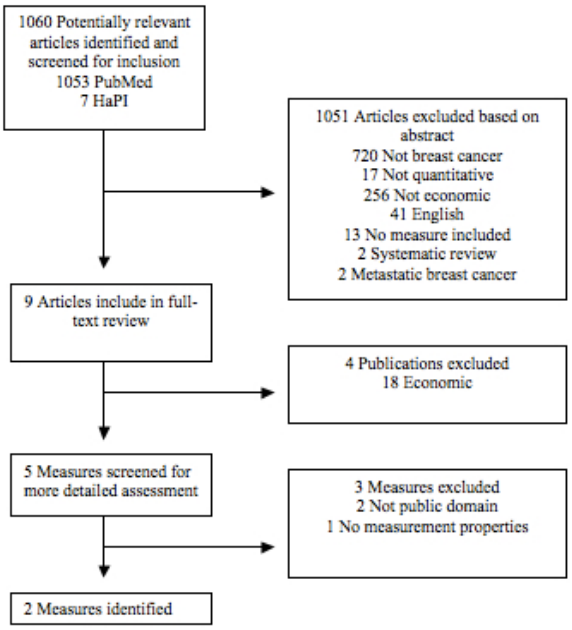
Appendix H Figure 1. Flowchart of search process for body image



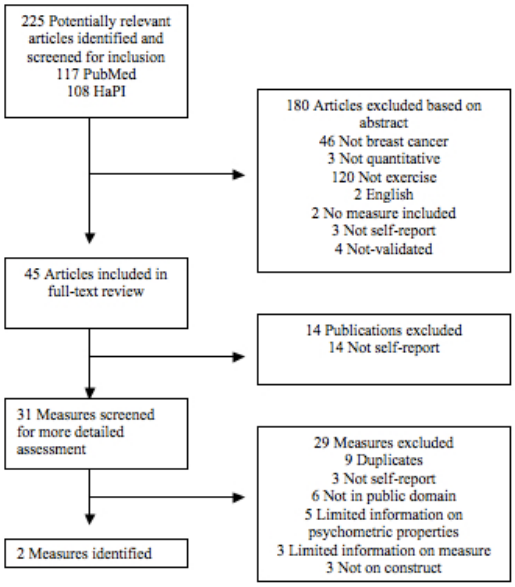
Appendix H Figure 2. Flowchart of search process for patient-provider communication



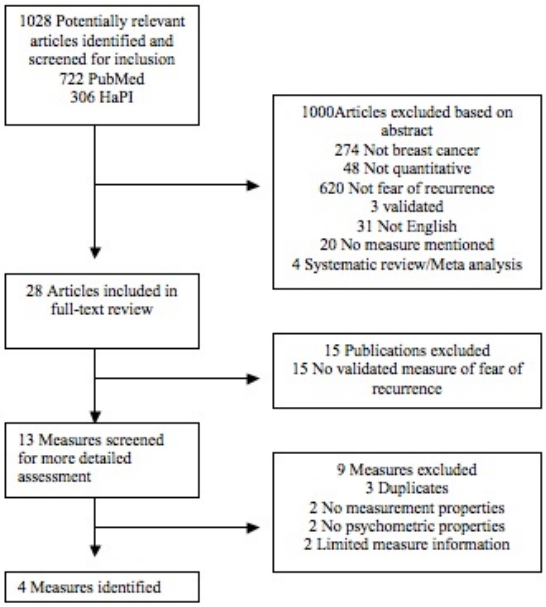
Appendix H Figure 3. Flowchart search process for diet



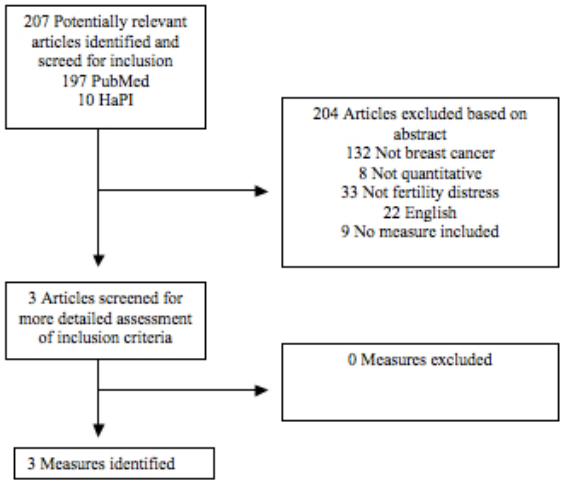
Appendix H Figure 4. Flowchart search process for economic



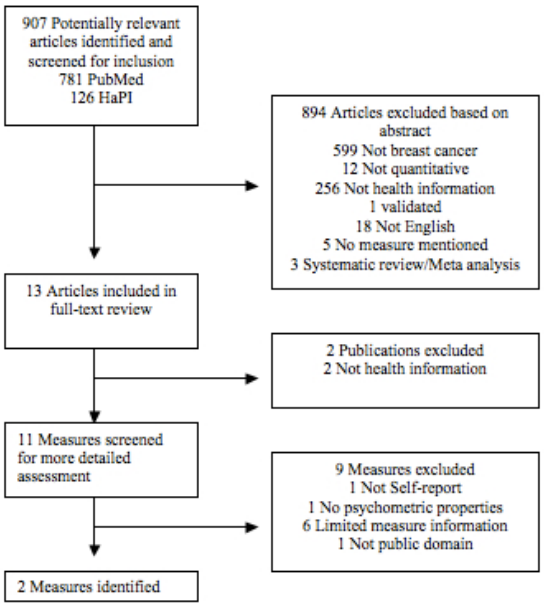
Appendix H Figure 5. Flowchart of search process for exercise



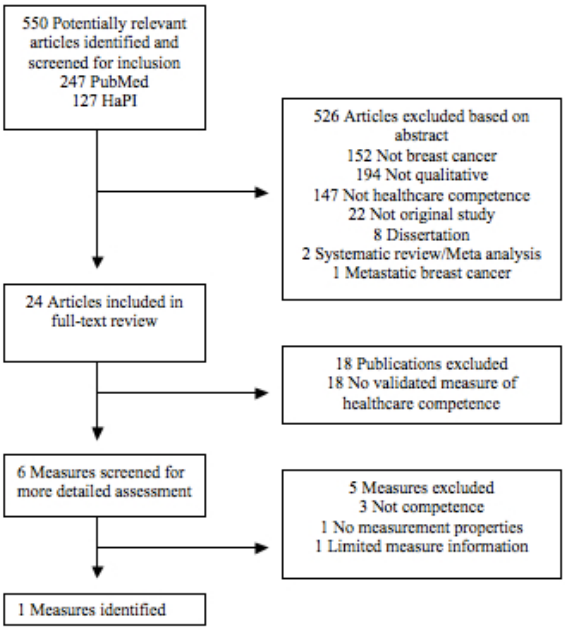
Appendix H Figure 6. Flowchart search process for fear of recurrence



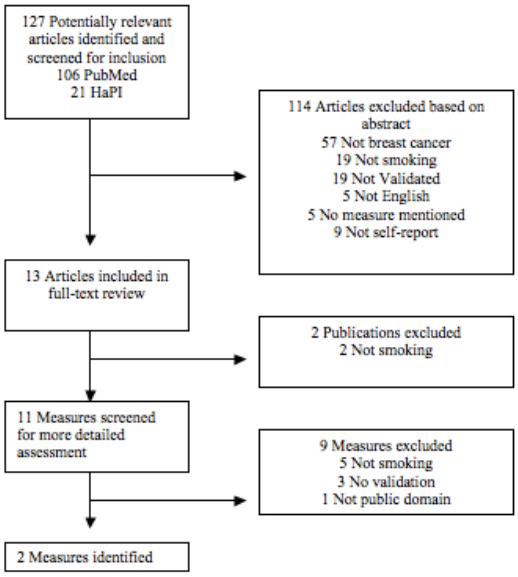
Appendix H Figure 7. Flowchart of fertility distress selection process



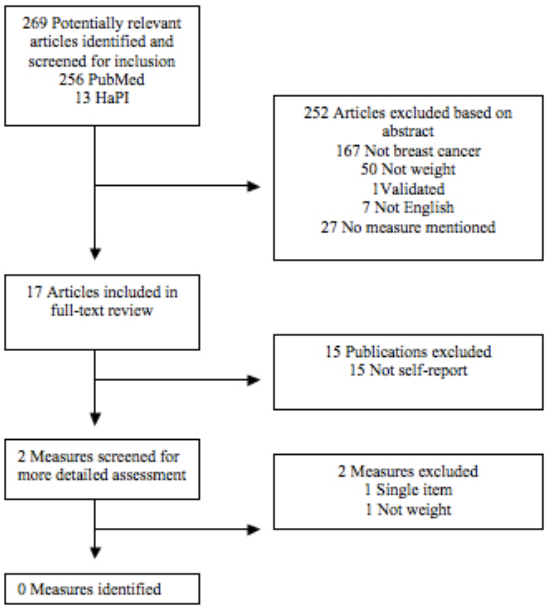
Appendix H Figure 8. Flowchart of search process for health information



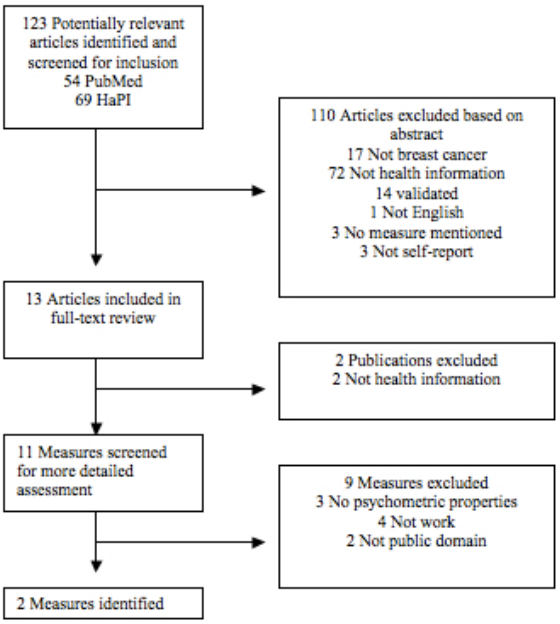
Appendix H Figure 9. Flowchart of search process for healthcare competence



Appendix H Figure 10. Flowchart of search process for cigarette smoking



Appendix H Figure 11. Flowchart of search process for weight



Appendix H Figure 12. Flowchart of selection process for work

Appendix I. Psychometric measurement properties of measures considered for inclusion in CSPro: Non-PROMIS

Appendix I

Fear of recurrence				
Measure	Sample	Sub-scale/Factor loading	Validity	Reliability
Impact of Cancer, version 2 (101)	BCS (101) BCS and Non-Hodgkin lymphoma (102)	Worry sub-scale (101) Factor loadings: 0.76-0.88	Concurrent validity: 0.32-0.33 (101) -0.52* - 0.57 (102) Construct validity: 0.34-0.59 (101) Split-sample cross validation. Factor structure replicated in Crespi et al., (102) with Non-Hodgkin lymphoma	Internal consistency reliability: α = 0.89 (101)
Quality of Life in Adult Cancer Survivors (20)	Heterogeneous sample survivors (N =242) (20) BCS (N=94) (19)	Distress Recurrence Sub-scale (20) Factor loadings: 0.75-0.85	Convergent validity: -0.67 (20) Divergent validity: -0.32- (-0.39) (19) Construct validity: 0.26-0.48(20) Retrospective validity: 0.25-0.38 (19) Responsiveness to life changes: Effect size 0.3, Reliable change index 0.75 (Negative change); Effect size 0.05, Reliable change index 0.13 (Positive change) (19)	Internal consistency reliability: α = 0.86 (20) Test-Retest reliability: 0.85 (19)
Cancer Worries Inventory (104)	Heterogeneous sample cancer patients (N= 185)	Death Sub-scale Factor loadings: 0.75-0.88	Convergent validity: 0.30-0.79 Divergent validity: -0.34- (-0.69)	Internal consistency reliability: α = 0.92
Quality of Life- Cancer Survivors (136)	Heterogeneous sample survivors (N= 686) (136) Heterogeneous sample childhood cancer survivors (N=177) (399)	Factor 2 (136) Factor loadings: 0.82-0.89 Factor 2 was replicated as Factor 3 (399)	Content validity: Expert review at City of Hope (136) Predictive validity: Total score accounted for 91% of variance (136) Concurrent validity: 0.42-0.81 (136)	Internal consistency reliability: α = 0.89 (136) Test-retest reliability: 0.88 (136)
Fertility distress				
Measure	Sample	Sub-scale/Factor loading	Validity	Reliability
Quality of Life- Cancer Survivors (136)	Heterogeneous sample survivors (N= 686) (136) Heterogeneous sample childhood cancer survivors (N=177) (399)	Factor 7 (136) Factor loading: 0.72 (Fertility) Factor 4 (399)	Content validity: Expert review at City of Hope (136) Predictive validity: Total score accounted for 91% of variance (136)	Internal consistency reliability: α = 0.77 (136) 0.18 (399) Test-retest reliability: 0.86 (136)

		Factor loading: 0.51 (Menstrual/fertility changes)	Concurrent validity: 0.74 (136)	
Infertility Reaction Scale (202)	Swedish couples seeking in-vitro (N =91)	Factor 1 (in women) Factor loading: 0.82 (Thinking about infertility)	Not available	Not available
The Fertility Problem Inventory (281)	Couples (n = 1,153 women; n = 1,149 men) (281) Greek women undergoing fertility treatment (N=108) (177)	Social Concerns (177) Factor loadings: 0.69-0.80	Convergent validity: 0.16-0.53; (281) 0.20-0.58 (177) Divergent validity: 0.26-0.66 (281) Concurrent validity: 0.25-0.56 (177)	Internal consistency reliability: α = 0.80- 0.87 (281) α = 0.79- 0.84 (177) Test-retest reliability: 0.83 (281)
Exercise				
Measure	Sample	Sub-scale/Factor loading	Validity	Reliability
Physical Activity Questionnaire (180)	Women (N=851) (180) Women (N=936) (384) Women (N=476) (21)	Full scale Factor loadings: Not available	Construct validity: Sub-scale positively associated with high-density lipoprotein cholesterol and inversely associated with insulin levels and fibrinogen (180); Total score positively correlated with functional capacity in METS during treadmill exercise testing (21) Predictive validity (all total score): OR 0.91 95% CI (0.82-0.999), p = 0.048 for likelihood of obstructive coronary artery disease; Adjusted risk of all adverse event HR 0.93 95% CI (0.88-0.99); Adjusted risk of major adverse events HR 0.88 95% CI (0.78-0.99) (384) Divergent validity: Total score associated with higher BMI; Total score lower for women with metabolic syndrome or diabetes (384)	Not available
Brief Cancer Impact Assessment (5)	BCS (N = 783)	Exercise and Diet Factor loading: 0.88 (Your exercise activities)	Convergent validity: 0.15-0.31 Divergent validity:	

			-0.10 – (-0.21)	
Health information				
Measure	Sample	Sub-scale/Factor loading	Validity	Reliability
Supportive Care Needs- Short Form (45)	Heterogeneous group of patients (n=888, n=250)	Heath Systems and Information Factor Factor loadings: 0.78-0.85	Known groups difference: Patients in active treatment had higher scores than those in remission Convergent validity: 0.48-0.56	Internal consistency reliability: $\alpha = 0.96$
Cancer Survivors Unmet Need Measure (205)	Heterogeneous group of survivors (N=353)	Information Factor loadings: 0.66-0.92	Face validity/Content validity: Subjective feedback Concurrent validity: 0.44-0.62 Construct validity: 0.38-0.45 Divergent validity: -0.20	Internal consistency reliability: $\alpha = 0.96$ Test-retest reliability: 0.23
Health competence				
Measure	Sample	Sub-scale/Factor loading	Validity	Reliability
Perceived Health Competence Scale (PHCS) (334)	5 samples: 1. Rheumatoid arthritis (n = 238) 2. Middle management positions at a southeastern university (n = 100) 3. Undergraduates (n = 186) 4. Undergraduates (n = 54) 5. West Point cadets (n = 528) (334) Medical patients (n = 320) (108)	Single Factor (108) Factor loading: 0.74-0.83	Divergent validity: -0.44 - (-0.55) (334) Construct validity: Higher PHCS, less need for advice and less need for health checks (108) Concurrent validity: 0.54-0.71 (108)	Internal consistency reliability: $\alpha = 0.82 - 0.90$ (334); 0.91 (108) Test-retest reliability: 0.82 (1 week), 0.6 (2.5 years) (334)
Work				
Measure	Sample	Sub-scale/Factor loading	Validity	Reliability
Impact of Cancer version 2 (101)	BCS (N =1188)	Employment Concerns Factor loadings: 0.67-0.93	Concurrent validity: 0.35 Construct validity: 0.39-0.44	Internal consistency reliability: $\alpha = 0.76-0.80$
Work Ability Index (368)	Occupational (N =371) (249) Nurses international sample (N = 40,000) (301)	Single factor Factor loadings 0.43-0.84 (249); 0.71-0.83 (301)	Convergent validity: 0.62 Divergent validity -0.52- (-0.54)	Internal consistency reliability: $\alpha = 0.54-0.78$
Economic				
Measure	Sample	Sub-scale/Factor loading	Validity	Reliability
Brief Cancer Impact Assessment (5)	BCS (N = 783)	Caregiving/Finances Factor loading: 0.90 (Your ability to care or provide for your children)	Convergent validity: 0.15-0.32 Divergent validity: -0.10-(-0.21)	Internal consistency reliability: $\alpha = 0.77$
Quality of Life in Adult Cancer Survivors (20)	Heterogeneous sample survivors (N=242) (20)	Financial Problems (20)	Construct validity: 0.26-0.54 (20)	Test-retest reliability: 0.82 (19)

	BCS (N=94) (19)	Factor loadings: 0.83-0.95	Convergent validity: 0.57 Financial problems correlated with Economic strain (.57) (20) Divergent validity: -.0.21 (20); -0.32-0.39 (19) Retrospective validity: 0.25-0.38 (19)	
Patient-provider communication				
Measure	Sample	Sub-scale/Factor loading	Validity	Reliability
Patient Satisfaction and Quality in Oncological Care (227)	Heterogeneous sample of patients and survivors, German (N=2,659)	Patient-provider relationship Factor loadings: 0.67-0.86	Convergent validity: -0.16-0.04	Internal consistency reliability: α = 0.71-0.87
Perceived Efficacy in Patient-Physician Interactions (246)	Geriatric (N=163)	Single factor Factor loadings: 0.70-0.84	Convergent validity: 0.17-0.55 Divergent validity: -0.27	Internal consistency reliability: α = 0.90-0.91
Modified-Patient Perceived Involvement in Care Scale (335)	Breast cancer patients (N=87)	Health Care Provider-Interaction Factor loadings: 0.76-0.90	Convergent validity: 0.80 Divergent validity: -0.23-(-0.50)	Internal consistency reliability: α = 0.90
Cigarette smoking				
Measure	Sample	Sub-scale/Factor loading	Validity	Reliability
National Social Life, Health, and Aging Project Questions on Cigarettes (120)	Community sample (N = 3,005)	No factor analysis	Construct validity: Associated with continine levels and explained about 90% of variance of number of cigarettes per day of current smokers.	Not available
Fagerstrom Test for Nicotine Dependence (193)	Cigarette smokers (N=254)	No factor analysis	Construct validity: Associated with continine levels, explaining 24.6 Log R^2	Internal consistency reliability: α = 0.61
Diet				
Measure	Sample	Sub-scale/Factor loading	Validity	Reliability
Multifactor Screener (360)	Development (n = 9,323) Testing (n = 484, n= 462, n =416)	No factor analysis	Construct validity: 0.50-0.80	Not available
Body image				
Measure	Sample	Sub-scale/Factor loading	Validity	Reliability
The Long-Term Quality of Life-Breast Cancer Scale (173)	BCS (N=285)	Body Image Factor loadings: 0.67-0.84	Construct validity: 0.33-0.67 Divergent validity: -0.23-0.24	Internal Consistency reliability: α = 0.83
Impact of Cancer, version 2 (101)	BCS (N=1,188)	Appearance concerns Factor loadings 0.69-0.86	Concurrent validity: 0.31-0.35 Construct validity: 0.45-0.48	Internal consistency reliability: α = 0.78

BCS = Breast cancer survivors
*In expected direction

Appendix J. Item descriptive statistics and Pearson item-scale correlations corrected for overlap

Table J1. Item descriptive statistics and Pearson item-scale correlations corrected for overlap

			Pearson item-scale correlations[a]					
Item	Mean	SD	A	P	FR	BI	F	DI
Sub-scale = A (Anxiety)								
Anxious	2.58	1.12	**0.78**	0.19**	0.47**	0.21**	0.41**	0.52**
Tense	2.65	1.04	**0.77**	0.29**	0.44**	0.36**	0.46**	0.58**
Emotional	2.67	1.01	**0.65**	0.26**	0.36**	0.26**	0.41**	0.60**
Irritable	2.59	0.97	**0.64**	0.26**	0.31**	0.31**	0.42**	0.54**
Fearful	2.09	1.09	**0.70**	0.22**	0.44**	0.23**	0.35**	0.63**
Sub-scale = P (Pain)								
Severe	2.36	1.09	0.24**	**0.84**	0.13*	0.23**	0.42**	0.29**
Interfere	2.28	1.07	0.24**	**0.84**	0.19**	0.28**	0.44**	0.31**
Joint	2.59	1.23	0.24**	**0.71**	0.21**	0.16*	0.39**	0.27**
Daily activities	2.46	1.16	0.29**	**0.83**	0.20**	0.30**	0.53**	0.35**
Burning	2.17	1.23	0.27**	**0.74**	0.14*	0.28**	0.42**	0.31**
Sub-scale = FR (Fear of recurrence)								
Cancer health	3.70	1.06	0.37**	0.19**	**0.74**	0.25**	0.37**	0.31**
Worry future	3.54	1.16	0.51**	0.24**	**0.81**	0.33**	0.41**	0.43**
Cancer unsure	3.50	1.14	0.44*	0.21**	**0.81**	0.29**	0.39**	0.42**
Coming back	3.86	1.02	0.36*	0.07	**0.75**	0.26**	0.34**	0.32**
New symptoms	3.78	1.06	0.34*	0.06	**0.63**	0.23**	0.23**	0.31**
Worry health	3.66	1.02	0.46**	0.22*	**0.77**	0.36**	0.41**	0.40**
Sub-scale = BI (Body image)								
Cover body	3.14	1.31	0.28**	0.24**	0.28**	**0.72**	0.29**	0.35**
Disfigured	3.18	1.28	0.25**	0.21**	0.26**	**0.71**	0.28**	0.27**
Body looks	3.34	1.20	0.36**	0.30**	0.37**	**0.74**	0.35**	0.27**
Sub-scale = F (Fatigue)								
Fatigued	2.93	1.09	0.47**	0.46**	0.41**	0.30**	**0.90**	0.47**
Run-down	2.92	1.06	0.41**	0.44**	0.41**	0.33**	**0.86**	0.48**
Energy	2.78	1.17	0.45**	0.46**	0.36**	0.30**	**0.84**	0.46**
Experience fatigue	2.88	1.14	0.49**	0.48**	0.46**	0.34**	**0.86**	0.47**
Rest	2.42	1.13	0.35**	0.42**	0.28**	0.29**	**0.71**	0.31**
Sub-scale = DS (Depressive symptoms)								
Look forward to	1.89	1.05	0.57**	0.30**	0.34**	0.34**	0.42**	**0.79**
Cheer me up	2.09	0.99	0.61**	0.34**	0.40**	0.31**	0.46**	**0.82**
Unhappy	2.32	0.93	0.64**	0.31**	0.41**	0.34**	0.45**	**0.83**
Depressed	2.26	1.06	0.67**	0.31**	0.45**	0.38**	0.44**	**0.84**

[a]Item-scale correlations are corrected for overlap and displayed in bold
*0.05 **0.01
Abbreviations: A = Anxiety, P = Pain, FR = Fear of recurrence, BI = Body Image, F = Fatigue, DI = Depressive symptoms

Appendix J2. Item descriptive statistics and Pearson item-scale correlations corrected for overlap

			Pearson item-scale correlations[a]				
Item	Mean	SD	CF	SR	S	SF	W
Sub-scale = CF (Cognitive function)							
Thinking slow	3.10	1.22	**0.86**	0.18**	0.39**	0.16**	0.41**
Shifting back and forth	2.74	1.32	**0.85**	0.21**	0.36**	0.15*	0.44**
Mental quality of life	2.68	1.29	**0.85**	0.17**	0.34**	0.12	0.43**
Concentrating	2.90	1.22	**0.88**	0.23**	0.36**	0.11	0.40**
Fog	2.60	1.28	**0.86**	0.15*	0.34**	0.11	0.36**
Trouble finding words	3.12	1.27	**0.73**	0.15*	0.36**	0.19**	0.33**
Sub-scale = SR (Social relationships)							
Helpful advice	3.84	0.99	0.16*	**0.80**	0.19*	0.17**	0.33*
Someone will listen	4.15	1.01	0.14*	**0.78**	0.11	0.16**	0.29*
Someone understands	3.80	1.10	0.18*	**0.80**	0.22**	0.16*	0.32**
Someone to help	4.10	1.02	0.24*	**0.78**	0.20**	0.14*	0.39**
Sub-scale = S (Sleep)							
Problem sleep	2.95	1.29	0.40**	0.20**	**0.88**	0.16**	0.28**
Sleep restless	2.98	1.30	0.33**	0.14*	**0.82**	0.13*	0.19**
Sleep quality	3.06	1.04	0.36**	0.20**	**0.84**	0.20**	0.27**
Satisfied sleep	3.35	1.22	0.39**	0.21**	**0.81**	0.21**	0.20**
Sub-scale = SF (Sexual function)							
Interested sexual activity	3.83	1.07	0.16*	0.17*	0.19*	**0.80**	0.18**
Sex	3.63	0.97	0.15*	0.17*	0.18*	**0.80**	0.10
Sub-scale = W (Work)							
Work ability	1.27	1.29	0.44**	0.38**	0.24**	0.12*	**0.84**
Physical demands work	2.17	1.12	0.42**	0.34**	0.26**	0.16**	**0.84**

[a]Item-scale correlations are corrected for overlap and displayed in bold

*0.05 **0.01

Abbreviations: CF = Cognitive function, SR = Social relationships, S = Sleep, SF = Sexual function, W = Work

Table J3. Item descriptive statistics and Pearson item-scale correlations corrected for overlap

			Pearson item-scale correlations[a]		
Item	Mean	SD	D	E	A[b]
Sub-scale = D (Diet)					
Bacon or sausage	1.90	0.80	**0.58**	0.05	0.15*
Hot dog	1.62	0.69	**0.55**	0.11	0.14*
French fries	2.02	0.81	**0.50**	0.13*	0.12
Sub-scale = E (Exercise)					
Work physical activity	1.99	0.78	0.02	**0.40**	0.00
Home physical activity	2.40	0.74	-0.19**	**0.40**	-0.01
Sub-scale = A (Alcohol consumption)					
Risks drank	1.30	0.64	0.22**	0.09	**0.52**
Drinking created problems	1.11	0.40	0.29**	-0.08	**0.52**

[a]Item-scale correlations are corrected for overlap and displayed in bold
[b]Used full sample with non-alcohol consumers calculated as "0"
*0.05 **0.01
Abbreviations: D = Diet, E = Exercise, A = Alcohol consumption

Appendix J4. Item descriptive statistics and Pearson item-scale correlations corrected for overlap

			Pearson item-scale correlations[a]			
Item	Mean	SD	C	HI	HC	EB
Sub-scale = C (Patient-provider communication)						
Ask doctor questions	1.66	0.92	**0.75**	0.07	0.26**	0.07
Doctor answer questions	1.89	0.96	**0.79**	0.21**	0.26**	0.16**
Explain health concern	1.75	0.92	**0.76**	0.12*	0.33**	0.04
Health concern seriously	1.98	1.02	**0.85**	0.22*	0.38**	0.17**
Get doctor to do something	2.14	1.07	**0.81**	0.20**	0.40**	0.14*
Ask doctor for more information	1.64	0.89	**0.70**	0.21**	0.21**	0.09
Sub-scale = HI (Health information)						
Written information	1.81	1.07	0.15*	**0.84**	0.19**	0.25**
Explanation tests	1.98	1.13	0.19**	**0.83**	0.20**	0.28**
Informed treatments	2.16	1.30	0.21**	**0.81**	0.17**	0.25**
Informed test results	2.08	1.21	0.11	**0.81**	0.15*	0.31**
Informed things to get yourself well	2.27	1.29	0.21**	**0.76**	0.25**	0.31**
Information internet	2.03	1.16	0.16**	**0.70**	0.15*	0.34**
Sub-scale = HC (Health competence)						
Health doesn't turn out	2.85	1.17	0.229**	0.20**	**0.77**	0.28**
Effective solutions to health problems	2.67	1.17	0.38**	0.23**	**0.72**	0.28**
Change healthcare ineffective	2.74	1.01	0.21**	0.18**	**0.78**	0.20**
My plans for my health	2.64	1.01	0.23**	0.18**	**0.77**	0.26**
Goals health	2.58	0.94	0.35**	0.18**	**0.72**	0.13*
Projects improve health	2.57	0.94	0.34**	0.15*	**0.68**	0.15*
Sub-scale = ED (Economic demands)						
Cost of cancer	2.24	1.39	0.11	0.30**	0.19**	**0.78**
Insurance	1.87	1.21	0.04	0.30**	0.20**	**0.54**
Money problems	2.48	1.48	0.13*	0.30**	0.24**	**0.86**
Loss of income	2.16	1.48	0.16*	0.25**	0.28**	**0.65**

[a]Item-scale correlations are corrected for overlap and displayed in bold
*0.05 **0.01
Abbreviations: C = Patient-provider communication, HI = Health information, HC = Health competence, ED = Economic demands

Appendix K. Cancer Survivor Profile: Reduced measure

Cancer Survivor Profile

Given your life as it is now, how do you feel about having had cancer?
Mark the box that best describes how much you agree or disagree with each statement.

1. Having had cancer makes me feel uncertain about my health.
   1 = Strongly disagree
   2 = Disagree
   3 = Neutral
   4 = Agree
   5 = Strongly agree
2. I worry about the future.
   1 = Strongly disagree
   2 = Disagree
   3 = Neutral
   4 = Agree
   5 = Strongly agree
3. Having had cancer makes me feel unsure about the future.
   1 = Strongly disagree
   2 = Disagree
   3 = Neutral
   4 = Agree
   5 = Strongly agree
4. I worry about cancer coming back.
   1 = Strongly disagree
   2 = Disagree
   3 = Neutral
   4 = Agree
   5 = Strongly agree
5. New symptoms make me worry about the cancer coming back.
   1 = Strongly disagree
   2 = Disagree
   3 = Neutral
   4 = Agree
   5 = Strongly agree
6. I worry about my health.
   1 = Strongly disagree
   2 = Disagree
   3 = Neutral
   4 = Agree
   5 = Strongly agree
7. I feel disfigured.
   1 = Strongly disagree
   2 = Disagree
   3 = Neutral

4 = Agree
5 = Strongly agree

8. I sometimes wear clothing to cover parts of my body.
   1 = Strongly disagree
   2 = Disagree
   3 = Neutral
   4 = Agree
   5 = Strongly agree
9. I worry about how my body looks.
   1 = Strongly disagree
   2 = Disagree
   3 = Neutral
   4 = Agree
   5 = Strongly agree

The next set of questions relate to how you view your health.
Mark the box that best describes how much you agree or disagree with the statement.

10. No matter how hard I try, my health just doesn't turn out the way I would like.
    1 = Strongly disagree
    2 = Disagree
    3 = Neutral
    4 = Agree
    5 = Strongly agree
11. It is difficult for me to find effective solutions to the health problems that come my way.
    1 = Strongly disagree
    2 = Disagree
    3 = Neutral
    4 = Agree
    5 = Strongly agree
12. I succeed in the projects I undertake to improve my health.
    1 = Strongly disagree
    2 = Disagree
    3 = Neutral
    4 = Agree
    5 = Strongly agree
13. I'm generally able to accomplish my goals with respect to my health.
    1 = Strongly disagree
    2 = Disagree
    3 = Neutral
    4 = Agree
    5 = Strongly agree
14. I find my efforts to change things I don't like about my health are ineffective.
    1 = Strongly disagree
    2 = Disagree

3 = Neutral
4 = Agree
5 = Strongly agree

15. Typically, my plans for my health don't work out well.
    1 = Strongly disagree
    2 = Disagree
    3 = Neutral
    4 = Agree
    5 = Strongly agree

The next set of questions ask about how confident you are in your ability to interact with your doctor.
Mark the box about how confident you are in your ability:

16. How confident are you in your ability to ask a doctor questions about your chief health concern?
    1 = Not at all
    2 = A little bit
    3 = Somewhat
    4 = Quite a bit
    5 = Very much
17. How confident are you in your ability to get a doctor to answer all your questions?
    1 = Not at all
    2 = A little bit
    3 = Somewhat
    4 = Quite a bit
    5 = Very much
18. How confident are you in your ability to explain your chief health concern to a doctor?
    1 = Not at all
    2 = A little bit
    3 = Somewhat
    4 = Quite a bit
    5 = Very much
19. How confident are you in your ability to get a doctor to take your chief health concern seriously?
    1 = Not at all
    2 = A little bit
    3 = Somewhat
    4 = Quite a bit
    5 = Very much
20. How confident are you in your ability to get a doctor to do something about your chief health concern?
    1 = Not at all
    2 = A little bit

3 = Somewhat
4 = Quite a bit
5 = Very much

21. How confident are you in your ability to ask a doctor for more information if you don't understand what he or she said?
    1 = Not at all
    2 = A little bit
    3 = Somewhat
    4 = Quite a bit
    5 = Very much

The next set of questions is about your relationship with others since the end of primary treatment (e.g., chemotherapy, radiation, surgery).
Mark the box that best describes how you feel about each statement.

22. I have someone who will listen to me when I need to talk.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Usually
    5 = Always
23. I have someone who understands my problems.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Usually
    5 = Always
24. I can get helpful advice from others when dealing with a problem.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Often
    5 = Always
25. Is someone available to help you if you need it?
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Usually
    5 = Always

The following questions ask about your ability to perform at work.
Mark the box that best describes how you feel about each statement.

26. Current work ability compared to your highest work ability ever:

How many points would you give your current work ability?
0 means that you cannot currently work and 5 is your work ability at its best.

0	1	2	3	4	5
completely unable to work					work ability at its best

27. Work ability in its relation to the demands of the job.
How do you rate your current work ability with respect to the **physical** demands of your work?
1 = Very good
2 = Rather good
3 = Moderate
4 = Rather poor
5 = Very poor

The next set of questions is about challenges you may have had in the past **7 days**.
Mark the box that best describes how you feel about each statement.
*In the past **7 days***

28. How much did pain interfere with your day-to-day activities?
1 = Not at all
2 = A little bit
3 = Somewhat
4 = Quite a bit
5 = Very much
29. How severe was your pain?
1 = Not at all
2 = A little bit
3 = Somewhat
4 = Quite a bit
5 = Very much
30. How severe was your joint pain?
1 = Not at all
2 = A little bit
3 = Somewhat
4 = Quite a bit
5 = Very much
31. How much did pain (e.g., back pain, arm pain, hand pain, hip pain, bone pain, muscle pain) affect your daily activities?
1 = Not at all
2 = A little bit
3 = Somewhat
4 = Quite a bit
5 = Very much

32. How much did you experience burning and/or sharp pain?

1 = Not at all
2 = A little bit
3 = Somewhat
4 = Quite a bit
5 = Very much

The next set of questions is about challenges you may have had in the past **7 days.**
Mark the box that best describes how you feel about each statement.
*In the past **7 days***

33. I was satisfied with my sleep.

1 = Not at all
2 = A little bit
3 = Somewhat
4 = Quite a bit
5 = Very much

34. My sleep was restless.

1 = Not at all
2 = A little bit
3 = Somewhat
4 = Quite a bit
5 = Very much

35. I had a problem with my sleep.

1 = Not at all
2 = A little bit
3 = Somewhat
4 = Quite a bit
5 = Very much

36. My sleep quality was.

1 = Very good
2 = Good
3 = Fair
4 = Poor
5 = Very poor

The next set of questions is about challenges you may have had in the past **7 days.**
Mark the box that best describes how you feel about each statement.
*In the past **7 days***

37. How run-down did you feel on average?

1 = Not at all
2 = A little bit
3 = Somewhat
4 = Quite a bit
5 = Very much

38. How fatigued were you on average?
    1 = Not at all
    2 = A little bit
    3 = Somewhat
    4 = Quite a bit
    5 = Very much
39. To what degree did you feel that you had no energy?
    1 = Not at all
    2 = A little bit
    3 = Somewhat
    4 = Quite a bit
    5 = Very much
40. How often did you need to rest during the day?
    1 = Not at all
    2 = A little bit
    3 = Somewhat
    4 = Quite a bit
    5 = Very much
41. How often did you experience fatigue?
    1 = Not at all
    2 = A little bit
    3 = Somewhat
    4 = Quite a bit
    5 = Very much

The next set of questions is about challenges you may have had in the past **7 days.**
Mark the box that best describes how you feel about each statement.
*In the past **7 days***

42. I felt like nothing could cheer me up.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Often
    5 = Always
43. I felt unhappy.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Often
    5 = Always
44. I felt depressed.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Often

5 = Always

45. I felt that I had nothing to look forward to.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Often
    5 = Always

The next set of questions is about challenges you may have had in the past **7 days.**
Mark the box that best describes how you feel about each statement.
*In the past **7 days***

46. I felt anxious.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Often
    5 = Always
47. I felt fearful.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Often
    5 = Always
48. I felt tense.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Often
    5 = Always
49. I felt very emotional.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Often
    5 = Always
50. I felt irritable.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Often
    5 = Always

The next set of questions is about challenges you may have had in the past **7 days.**
Mark the box that best describes how you feel about each statement.

*In the past **7 days***

51. My thinking has been slow.
    1 = Never
    2 = Rarely (Once)
    3 = Sometimes (Two or three times)
    4 = Often (About once a day)
    5 = Very often (Several times a day)
52. I have had trouble shifting back and forth between different activities that require thinking.
    1 = Never
    2 = Rarely (Once)
    3 = Sometimes (Two or three times)
    4 = Often (About once a day)
    5 = Very often (Several times a day)
53. My problems with memory, concentration, or making mental mistakes have interfered with the quality of my life.
    1 = Never
    2 = Rarely (Once)
    3 = Sometimes (Two or three times)
    4 = Often (About once a day)
    5 = Very often (Several times a day)
54. I have had trouble concentrating.
    1 = Never
    2 = Rarely (Once)
    3 = Sometimes (Two or three times)
    4 = Often (About once a day)
    5 = Very often (Several times a day)
55. My brain was in a fog.
    1 = Never
    2 = Rarely (Once)
    3 = Sometimes (Two or three times)
    4 = Often (About once a day)
    5 = Very often (Several times a day)
56. I have had trouble finding words when talking to someone.
    1 = Never
    2 = Rarely (Once)
    3 = Sometimes (Two or three times)
    4 = Often (About once a day)
    5 = Very often (Several times a day)

The next set of questions is about challenges you may have had in the past **30 days.**
Mark the box that best describes how you feel about each statement.
*In the past **30 days***

57. How interested have you been in sexual activity?

1 = Not at all
2 = A little bit
3 = Somewhat
4 = Quite a bit
5 = Very much

58. How often have you felt like you wanted to have sex?
1 = Never
2 = Rarely
3 = Sometimes
4 = Often
5 = Always

The next set of questions are about financial matters related to cancer.
Indicate how often each of these statements has been true for you in the past **30 days.**

59. You had financial problems because of the cost of cancer surgery or treatment.
1 = Never
2 = Rarely
3 = Sometimes
4 = Often
5 = Always
60. You had problems with insurance because of cancer.
1 = Never
2 = Rarely
3 = Sometimes
4 = Often
5 = Always
61. You had money problems that arose because you had cancer.
1 = Never
2 = Rarely
3 = Sometimes
4 = Often
5 = Always
62. You had financial problems due to a loss of income as a result of cancer.
1 = Never
2 = Rarely
3 = Sometimes
4 = Often
5 = Always

The next set of questions is about challenges you may have had in the past **30 days.**
Mark the box that best describes how you feel about each statement.
*In the past **30 days***

63. Did you drink any type of alcoholic beverage? (screener)
1 = Yes

2 = No (Skip to 66)

64. I took risks when I drank.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Often
    5 = Almost always
65. Drinking created problems between me and others.
    1 = Never
    2 = Rarely
    3 = Sometimes
    4 = Often
    5 = Almost always

Please think about what you usually ate or drank during the past month, that is, the past **30 days.** Please read each question and:
- Report how many times per day, week, or month you ate each food.

66. How many times per **day**, **week**, or **month** did you **usually** eat **bacon** or **sausage**, not including low fat, light, or turkey varieties?
    1 = Never
    2 = 1-3 times last month
    3 = 1-2 times per week
    4 = 3-4 times per week
    5 = 5-6 times per week
    6 = 1 time per day
    7 = 2 times per day
    8 = 3 times per day
    9 = 4 or more times per day
67. How often did you eat **hot dogs** made of beef or pork?
    1 = Never
    2 = 1-3 times last month
    3 = 1-2 times per week
    4 = 3-4 times per week
    5 = 5-6 times per week
    6 = 1 time per day
    7 = 2 times per day
    8 = 3 times per day
    9 = 4 or more times per day
68. How often did you eat **French fries, home fries,** or **hash brown potatoes**?
    1 = Never
    2 = 1-3 times last month
    3 = 1-2 times per week
    4 = 3-4 times per week
    5 = 5-6 times per week
    6 = 1 time per day

7 = 2 times per day
8 = 3 times per day
9 = 4 or more times per day

Below are questions about needs that you may have experienced as a result of having cancer. Mark the box that best describes whether you have needed help with these needs in the last **30 days**. There are 5 possible answers to choose from:

No Need	**1 Not applicable-** This was not a problem for me as a result of cancer.
	2 Satisfied- I did need help with this, but my need for help was satisfied at the time.
Some Need	**3 Low need-** This item caused me concern or discomfort. I had little need for additional help.
	4 Moderate need- This item caused me concern or discomfort. I had some need for additional help.
	5 High need- This item caused me concern or discomfort. I had a strong need for additional help.

69. Being given written information about important aspects of your care.
    1 = Not applicable
    2 = Satisfied
    3 = Low need
    4 = Moderate need
    5 = High need
70. Being given explanations of those tests for which you would like explanations.
    1 = Not applicable
    2 = Satisfied
    3 = Low need
    4 = Moderate need
    5 = High need
71. Being adequately informed about the benefits and side-effects of treatments before you choose to have them.
    1 = Not applicable
    2 = Satisfied
    3 = Low need
    4 = Moderate need
    5 = High need
72. Being informed about your test results as soon as feasible.
    1 = Not applicable
    2 = Satisfied
    3 = Low need
    4 = Moderate need
    5 = High need
73. Being informed about things you can do to help yourself get well.
    1 = Not applicable

2 = Satisfied
3 = Low need
4 = Moderate need
5 = High need

74. Being able to judge the quality of cancer related information provided on the Internet.

1 = Not applicable
2 = Satisfied
3 = Low need
4 = Moderate need
5 = High need

The next set of questions is about cigarette smoking.
Mark the box that best describes your experience with each statement.

75. Have you smoked at least 100 cigarettes in your entire life? (screener)

Note: 5 packs = 100 cigarettes

1 = Yes
2 = No
3 = Don't know / Not sure

76. Do you smoke cigarettes every day, some days, or not at all?

1 = Every day
2 = Some days
3 = Not at all
4 = Don't know / Not sure